

**FUNERAL DIRECTORS: HIDDEN VICTIMS OR COPERS?
and
RESEARCH PORTFOLIO**

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SECTION 1: MAJOR RESEARCH PROJECT LITERATURE REVIEW

The Experiences of Death, Disaster and Coping and the Role of the Funeral Director

Prepared in accordance with guidelines from:

MORTALITY
(appendix 1)

**THE EXPERIENCES OF DEATH, DISASTER AND COPING AND THE
ROLE OF THE FUNERAL DIRECTOR**

abbreviated title: Death, disaster, coping and the funeral director

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THE EXPERIENCES OF DEATH, DISASTER AND COPING AND THE ROLE OF THE FUNERAL DIRECTOR

ABSTRACT

The focus of this paper is the nature and manifestations of Post-Traumatic Stress Disorder (PTSD). Within this examination is a review of the literature concerning the populations who have suffered PTSD and have been researched as a result. In the main these populations have been emergency service workers for whom traumatic incidents, but not always death, are an integral part of their work. Consideration is made of the funeral directing profession. Here is a profession which can be identified as having death as the central aspect of its work. There is little known about this profession within which there are a select few who choose to specialise in disaster work. This review considers the evolution of deathwork in western societies and how, as a result, funeral directors have both a unique role and outlook on death. Whether the funeral director, separate from other professions, has a unique way of coping with the stresses of his profession is discussed in relation to the existing literature.

THE EXPERIENCES OF DEATH, DISASTER AND COPING AND THE ROLE OF THE FUNERAL DIRECTOR

THE EXPERIENCE OF DISASTER

Post-Traumatic Stress Disorder

Exposure to traumatic and extreme events has long been known to lead to a spectrum of symptoms. Trimble (1985) provides a good review of the recognition of the symptoms from the Great Fire of London through more recent accounts of battle fatigue to today's diverse phenomena of natural and contrived disasters.

The discrete syndrome of PTSD was first officially recognised as a clinical entity in The Diagnostic and Statistical Manual of Mental Disorders (DSM-III, American Psychiatric Association (APA), 1980). PTSD is categorised as an anxiety disorder which occurs when the individual experiences a specific event or series of events outside the usual range of experience. The characteristic symptoms of the disorder as currently described by DSM-IV (APA, 1994) include; cognitive or emotional re-experiencing of the event, avoidance of stimuli or reminders of the event and hyperarousal. These symptoms should exceed a duration of one month. The nature of the event usually involves a serious threat to one's own or other people's life. Sudden destruction of homes or communities, witnessing death, serious injury, or the aftermath of the disaster all lead to symptoms. Brooks and McKinley (1992) have also noted that being in close proximity to the dead bodies or to body parts was significant to the development of the disorder after the Lockerbie air disaster in 1989. DSM-IV (APA, 1994) now also acknowledge this as a trigger.

A number of factors have been identified as interacting with and possibly influencing the individuals experience, interpretation and vulnerability to the event and its consequences. These factors include: the nature of the event (i.e.

was the event man made or a natural disaster?); the presence of any pre-existing psychiatric symptomatology; previous life events; and, the coping style employed by the individual (McFarlane, 1988). Breslau and Davis (1992) suggest a lifetime prevalence of PTSD of 9.2% in the general population and a risk of other disorders such as major depression and alcohol abuse and or dependence. Men appear to be more at risk, especially if they have had a complicated life history. Women, however, tend to have a more chronic experience of symptoms.

Victims and Hidden Victims

The two broad groups generally identified as being at risk of suffering PTSD are disaster victims and workers. The definition disaster workers can encompass a wide range of personnel and generally include: those involved in direct rescue work; medical staff, who may work with both survivors and to some extent may be helping with direct rescue work; also, there are information and communication staff who may not be directly on site but in the vicinity; finally, support services for the patients and relatives. A myth appears to have developed that workers, because of the nature of their background and professionalism are in some way protected from suffering any distress. Emerging research, cited below, is indicating that this is not, in fact, the case.

The amount of research on disaster workers and PTSD symptomatology although increasing is still relatively sparse. The work has largely focused on those groups whose presence at the site of a disaster is known and acceptable i.e. fire fighters (McFarlane, 1992), 'disaster' teams (Mitchell, 1983; Raphael, 1981) and the police (Mitchell *et al*, 1991). Durham *et al* (1985) found that at 91% of those personnel 'on the scene' showed at least one symptom of PTSD.

Early on in the history of research into PTSD Kliman (1976) identified what he referred to as the 'hidden victim'. This refers to the personnel who arrive early on the scene, are likely to be apprehensive and whose role is to evaluate and plan the intervention and rescue work. He focused upon two american air crashes in the late 1970's and the 'gruesome and obnoxious aspects of handling the dead'

and the emotionally disturbing aspects of the work that lead to the experience of distress in workers. He argues that it is almost as though handling of the dead and the recognition of the stress from the task are both taboo subjects. Paton (1989) notes that workers create an expectation in themselves and in others that they are 'resourceful, powerful and able to fix what has happened'.

Mitchell (1990) notes that the worst part of the work at Lockerbie was mortuary duty and that time spent in the mortuary was inversely related to PTSD symptomatology i.e. the longer the exposure to the mortuary and its contents the more reduced the anxiety became. Animal studies may provide some insight into this as a primitive response. Bowlby (1973) suggests that there is some overlap between situations which arouse fear and anxiety in humans and primates. The main studies in this area have been carried out by Lawick-Goodall (1968) and Harlow (1959, 1961, 1965). Primates show fear and flight responses to a variety of threatening situations, one of which is the sight of other primates mutilated. A phenomenon also derived from animal studies is that of habituation i.e. that repeated exposure to a stimulus can change an animal's responsiveness to it (Dickinson, 1980).

Working with dead bodies and its possible effect in the development PTSD symptomatology has largely been ignored in the research. Indeed Taylor and Frazer (1982) felt that there was so little research it was almost a 'taboo research topic... the experiences of those unlucky enough to be assigned to recover bodies was intended not to be examined and incorporated into the corpus of behavioural studies'. Ten years on we are beginning to acknowledge its importance. Brooks and McKinlay (1992) and Dyregov and Mitchell (1992) report that seeing the dead bodies of children can lead to powerful emotional responses even in the very experienced. Only one piece of research could be identified which considers the coroners work (n=6) in a disaster situation that of Stuhlmeier (1994). This research identified that the coroners' participation, compared with other workers, was considered most consistent with their everyday work and was not interpreted as a 'critical incident'.

THE EXPERIENCE OF THE FUNERAL DIRECTOR

The History of Funeral Directing

Burials and the formal funeral have been observed in nearly all cultures throughout history. By the 1850's the function of the undertaker began to develop into the entrepreneur providing the services for a set charge. The tradition of handing the business down to the son was also emerging. By the turn of the century the manufacture of mortician's tools had become categorically separate from the function of the undertaker and they remain so today. From 1900 until today there has been an aesthetic shift by undertakers, for example they have changed their name to 'funeral directors' and thus the emphasis of their work has changed. There has been a dissociation from the 'coarseness' of what they do. No longer is the work carried out by the 'lower members of society' (Thompson, 1991).

In the last quarter of this century there has been a move towards the more 'dramatic' aspects of their work; putting chapels on the premises of the funeral home, with the clergy visiting the funeral home to carry out their function. As a result, over the years the funeral director has acquired more control and more recently governing bodies have been established to 'professionalise' their work (Habenstein, 1962). The language of the funeral director has also changed over the years with a move away from the harsh, grim and realistic towards the more detached and euphemistic e.g. 'slumber room'. As the profession has developed so has the stigma towards those who carry out what is essentially a job which violates social taboos (Thompson, 1991).

Today the funeral home is generally a 24 hour business with directors suggesting that their work demands a level of energy and spirit which is seldomly appreciated by the 'lay' public (Habenstein, 1962). The funeral director has to behave in a way which is appropriate to each death and is vulnerable to the whims and emotions of the bereaved. This constant striving to suit the needs and expectations of each family can, Habenstein argues, lead to stress and strain.

The media is beginning to profile the work of the funeral director e.g. 'Short Stories' Channel 4, (Dec, 1994). Innovative developments include the Funeralcare public exhibition held at the Scottish Exhibition and Conference Centre in December of 1994, the aim being 'Peace of mind through understanding'. The intention was 'to break down the traditional barriers surrounding the subject and provide a friendly and informal forum where the public can get information on a wide range of funeral and bereavement services'.

Research into the Profession of the Funeral Director.

Qualitative and sociological research into the funeral directing profession is available and has provided a rich seam of work. Notable descriptions of the profession include Mitford (1963), Habenstein (1962), Richardson (1987), Howarth (1993 and forthcoming). Although comprehensive these works are often restricted in their view because of the influence of a 'gatekeeper' to the profession. Howarth (1993) has commented on the difficulties of gaining access to members of this profession and that once gained any events and practices observed are given an explanation and interpretation by the funeral directors. The suggestion therefore is of a profession very protective of its work and how it may be perceived and reported.

Quantitative research into the profession is rare possibly due to this fear of interpretive reporting. The research which has been conducted has all been in the USA and has included broad topics such as how funeral directors view death and their work (Crouch, 1975; Benfield and Nichols, 1984; Schell and Zinger, 1985; Williams-Conway, 1991). The core of the quantitative research has been concerned with the development of scales and the measurement of: death attitudes (Kurlycheck, 1978-9; Calhoun *et al*, 1988-9); death concern (Dickstein, 1972); and, death anxiety (Templer, 1970; and Templer and Ruff, 1971; Ray and Najam, 1974; Pepitone-Arreola-Rockwell, 1981; Warren, 1981; Schell and Zinger, 1984). The general finding is that funeral directors have adaptive attitudes and low anxiety concerning death.

With respect to attitudes towards the funeral directing profession, again there is limited research. The historical view of the profession is that funeral directors have usurped the role of the clergy (Kalish and Goldberg, 1978). French (1985) found that the clergy were unhappy with the way funeral directors had taken over their role to a large extent and wished to see more simplicity in the process, less expense and a return to funerals being held in church. The public's attitude historically is one of scorn for the profit funeral directors make (Reynolds and Kalish, 1974; Charmaz, 1980) Most notable was Mitford's attack on the profession in 1963 and a perceived Dickensian attitude towards the work. Kalish and Goldberg (1979-80) argue that these attitudes prevail amongst the minority who have had little direct contact with the profession and that generally the view is of 'substantial acceptance and essential satisfaction'.

THE EXPERIENCE OF DEATHWORK

The Evolution of Deathwork

Kastenbaum and Aisenberg (1974) point out that exposure to death and death work was historically frequent, when death from old age was a rarity. As a result we frequently bore witness to death and its realities. They argue that this shaped our interpretations of death. Now the opposite is true, death tends to occur only to the elderly who are to some extent already removed from society (Jackson, 1980). Probably the most important time in history with respect to the prevalence of death was 14th century Europe. The Black Death influenced every individual and games, art, religion and literature reflect its impact on society and some practices still remain from this time. Embalming was first practised by the Egyptians and was used extensively during the Black Death to sterilise bodies and ensure death. This continues today under the same pretexts with the attitude that being able to view the body will aid the grief process (Charmaz, 1980).

Today we are more insulated from the reality of death, its details and processes. The work is carried out by professionals rather than by the family. This detachment has developed to such an extent that we now feel a sense of rage

when people die in the wrong place or at the wrong time i.e. in the context of disasters. Gorer (1965) argues that the role of the funeral director has developed as a result of our need to isolate ourselves from death. Reynolds and Kalish (1974) note that few people enter the job out of choice and that with the job comes the psychological dilemma and anxiety concerning one's own mortality. They suggest that there are four factors which keep funeral directors in work; job security, good pay, the opportunity to provide a necessary service and leeway i.e. the special privileges accrued to these workers. As a group they are marginalised and stigmatised in society (Howarth, 1993; Thompson, 1991) and often hesitate when disclosing their profession (Reynolds and Kalish, 1974). In an attempt to reduce the stigma they may redefine their work and emphasise the service providing aspects to it (Thompson, 1991).

The Semiotics of deathwork

The language of deathwork has been subject to analysis by socio-linguists. It has changed from the brutal and realistic to the metaphoric (Habenstein, 1962). Turner and Edgley (1976) carried out a dramaturgical analysis of the funeral director and the use of metaphor. What was revealed was that there are languages and behaviours reserved and separate for 'backstage' and 'frontstage'. Backstage is away from the family and the work is largely physical and tactile. Language includes a number of metaphors which are used as a way of distancing from the work e.g. 'floaters', 'pickling', 'bods', 'stiffs' etc. As with other professions engaged in taboo work humour is often part of the rhetoric and is often based upon real events (Reynolds and Kalish, 1974; McCammon *et al*, 1988).

Frontstage, the behaviour is markedly different and is in the style of an usher. The mood of the situation is dictated by the appropriate tone, volume and timing of speech and correct use of music. The rhetoric is one of sleep and eternal life. Turner and Edgley (1976) argue that the drama of the funeral is used to hide the function of the funeral which is to dispose of a body. Barley (1983) argues that the funeral director has a performance to give and the aim is to provide a scene of naturalness, and peacefulness. We are no longer as close to death on a day-to-

day level and so our reactions are more unpredictable and intense, something the funeral director has to be prepared for.

THE EXPERIENCE OF COPING

The Study of Coping

Lazarus and Folkman (1984) have defined coping as 'the process by which one manages the demands and emotions generated by that which is appraised as stressful'. It is acute stress which leads to the necessity for coping strategies to emerge. Usually when there has been an event or series of events which are sufficiently overwhelming to the individual, if the coping strategies are insufficient or inadequate in some way then PTSD may result. There is a good deal of literature on this subject, but as yet there is no clear theoretical framework, method of measuring coping, or even of defining stress (Dewe, 1991).

Approaches to the study of stress and coping have include: categorisation of different types of coping; individual styles of coping; examination of the links between stressors and strategies; and, the effects of recent events as an indicator of general coping style (Billings and Moos, 1984; Lazarus and Folkman, 1984). In examining coping strategies, however, three themes emerge in the literature: looking for meaning in the event; attempting to gain some mastery over the event; and, attempting to restore personal self-esteem through a re-evaluation of the event (McCammon *et al*, 1988). Duckworth (1986) suggests that active and varied strategies towards coping appear more effective than singular and passive responses. Martin *et al* (1986) studying PTSD reactions in police officers who were involved in working with victims found that coping was largely best done by women and by talking to fellow officers. Avoidance or distancing was not often used because of the lack of opportunity.

Research into coping is now beginning to focus on disaster workers, the 'hidden victims'. McCammon *et al* (1988) found that the strategies used were those of

reminding oneself of the help they were providing; reframing the event in a positive light; realistic worrying; looking for humour in the event; and, looking at the technical challenge in the event. Dealing with traumatised children can place specific demands upon the individual and Dyregov and Mitchell (1992) found distancing, shutting out of thoughts and feelings and concentrating on the job in hand were the main coping responses when the focus of work is children.

Coping with Deathwork

Deathwork is considered to be 'figuratively unclean' because it violates social taboos (Thompson, 1991). As a result, funeral directors tend to take a scientific view of their work as a way of countering the stigma which they feel is due to a misunderstanding of the nature of the work. Strategies are employed to reduce the stigma and include: symbolic redefinition of the work; role distancing; professionalism; and, an emphasis on the service being provided. Charmaz (1980) argues that the methods of coping used by funeral directors include: minimising; hiding; flaunting; and, acknowledgement. Reynolds and Kalish (1974) suggest that in order to hide or to come to terms with the anxiety associated with their work funeral directors focus on the business rather than the psychological aspects of their work.

Training tends to focus on the business side of the job. Interpersonal and emotional development come through experience. An attempt is made to routinise death through a separation of work and workers from ordinary parts of the premises (Charmaz, 1980). Howarth's ethnographic study of funeral directing (forthcoming) suggests that in order to do their work they must suspend society's preconceived notions and construct a new morality which enables them to carry out the work that others find repugnant. She argues that the morality they devise is one based upon accounting and neutralising tactics. These include: avoidance; dehumanisation; distancing; focusing on the essential nature of the work; professionalising; and, the development of a different typology of death i.e. one which is based upon the body and not on any knowledge of the person.

The work of death and dealing with dead bodies is a daily feature of the funeral directing profession. The suggestion has been made (Howarth, forthcoming) that in order to do this work they have to make some adjustments to their morality. Also amongst the profession is a small subgroup who, although not widely known about, specialise in 'disaster work'. In the literature on occupational stress, disasters and especially PTSD there is a gap, which may be of clinical importance to the future development of initial diffusing techniques and critical incident debriefing. There has not been any psychological evaluation of the funeral director nor any evaluation of their coping strategies in terms of the work they do generally or in disaster situations. The question then is twofold: What is the emotional experience of the funeral director, and is there anything we can learn with respect to deathwork, disasters and coping?

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SECTION 2: MAJOR RESEARCH PROJECT PROPOSAL

Prepared in accordance with guidelines from:

The D.Clin.Psy. course handbook description of The Chief Scientists Office mini-
project grant application guidelines
(appendix 1)

RESEARCH PROPOSAL

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TITLE: Funeral Directors: Hidden Victims or Copers?

SUMMARY:

The following is a proposal for a research project focusing on the experience of the funeral director in the light of the recent increase in research on Post Traumatic Stress Disorder (PTSD). Research has largely focused upon those who have been involved in disaster teams. Until now there has been no research on the experience of the funeral director in this respect. Previous research with funeral directors has focused upon sociological and qualitative issues. The funeral director has the unique daily experience of factors thought to act as triggers to PTSD such as seeing and working with dead bodies and body parts. Some funeral directors furthermore work in disaster situations and so are directly exposed to traumatic situations. The aim of this research is to describe this population in a quantitative manner, using clinical and descriptive measures. Areas which will be investigated in this study include: general health and mood; attitudes towards death; and, work and coping strategies. The study will be carried out on a sample of funeral directors working in the west of Scotland and will include a sub-sample of funeral directors involved in disaster work.

INTRODUCTION

A wide body of research has emerged over the last 10 years or so on the anxiety disorder of Post-Traumatic Stress, looking at both the populations who suffer the disorder, and the situations which cause the disorder. The two broad groups identified as suffering from PTSD are disaster victims and workers. The events described are usually outside the normal range of experience, and invariably they are natural or contrived disasters.

Kliman (1976) identified the workers in these situations as the 'hidden victims', and since then research has highlighted their various and specific problems. In the main research has focused upon police officers (Mitchell *et al*, 1991), firefighters (McFarlane, 1992) and disaster teams (Mitchell, 1983; Raphael, 1981). Amongst the research, there are only three occasions where proximity to dead bodies or body parts and PTSD are linked (Brooks and McKinley, 1992; Mitchell, 1990; and, DSM-IV, 1994). Body handling and its effect upon the development of PTSD has otherwise largely been ignored by the literature. Although working with dead bodies is accepted as a part of disaster work, it is regarded as almost a 'taboo research topic' (Taylor and Frazer, 1982). There is only one piece of research within the psychological literature which considers the work of the coroner at a disaster site (Stuhlmiller, 1994).

Occupational stress and the psychological profiling of a variety of professions exists in the literature. Research covers a wide range of both white and blue-collar workers (See Mackay and Cooper, 1987 and Pekrun and Frese, 1992 for comprehensive reviews). The funeral directing profession has provided a good deal of information from the sociological and qualitative perspectives and has focused largely on American populations. Quantitative research on this profession is scarce and focuses on death anxiety, concern and attitudes. The adjustment and psychological aspects of the funeral directors and the contexts of their job have thus far not been examined.

In linking the notions of PTSD and the possible effects of body handling it would appear that no research has been conducted on the population who deals directly with death and deathwork on a daily basis, namely funeral directors, to see what experience they may have. With the increase in the frequency of traumatic and untimely deaths occurring in disasters the role of the funeral director has changed requiring more skill in embalming and reconstruction work and in some cases to work on bodies at the scene of a disaster.

It is of clinical importance to determine a psychological profile of this population, to consider what anxiety their work causes, and how they cope with it. This will be of importance for future clinical work with populations who have not developed such coping skills when working with the dying, dead or bereaved i.e professionals involved in police and disaster work.

AIMS AND HYPOTHESES

The aims of the project are:

- 1- To gain a brief psychological profile of funeral directors.
- 2- To measure attitudes to death which has been done before on American populations of funeral directors to see how the two populations compare.
- 3- To measure specific issues of occupational stress and coping methods to further understand the coping strategies of this population.
- 4- To compare those funeral directors who are and are not involved in disaster work to examine and consider any differences.

The hypotheses of the project are:

- 1- That funeral directors will generally score within the normal range on the psychological measures used although those involved directly in disaster work may experience less symptoms suggestive of anxiety and PTSD.
- 2- With respect to the measures that have been used before in the USA it is hypothesised that in the UK funeral directors show similar low scores indicative of functional attitudes and adjustment towards death.
- 3- With respect to measures of occupational stress and coping it is hypothesised that this population will have comprehensive and varied coping strategies, and that funeral directors involved in disaster work cope more effectively.

PLAN OF INVESTIGATION

Consent will be sought via the contact persons, the Strathclyde regional representative of the National Association of Funeral Directors and the coordinator of Kenyons Emergency Services (KES). A letter explaining the format, aims and requirements of the project will be sent out (appendix 2). This letter will be accompanied by a consent form (appendix 3). Those who wish to take part will have their name and contact address released to the researcher. Following the receipt of the consent form a questionnaire (appendix 4) will be dispatched to the funeral director. Subjects will be given the opportunity to contact the researcher to ask any questions or clarify any issues concerning the questionnaire at any time. The projected sample size is 20.

Subjects

Twenty funeral directors working either in the West of Scotland or with KES will be asked to take part in the study by their contact person. It is also hoped that a good proportion of these will be involved in disaster work either through their normal work or as a member of KES.

Measures

Contents of the self-report questionnaire (appendix 4) are as follows:

Section 1: Background Information.

This consists of general demographic data concerning the individual and their work

Section 2: Health and Mood

The 28 item General Health Questionnaire (Goldberg and Hillier, 1979) is used to determine the presence of clinical and subclinical distress and the disruption in functioning. There is evidence to suggest a high predictive validity for post traumatic stress (Duckworth, 1990; McFarlane, 1992).

Hospital Anxiety and Depression scale (Zigmond and Snaith, 1983). A broad scale often used in clinical practice is suggested here to gain a picture of the presence of clinical caseness for anxiety and depression in this population.

Penn Inventory (Hammarberg, 1992)

This relatively new scale will be used to determine the presence of PTSD in the funeral directors. Previously used on Piper Alpha survivors it is preferable to the Impact of Events Scale as it goes beyond the basic symptomatology of intrusion and avoidance associated with the disorder.

Section 3: Attitudes to death

Death Anxiety and Death Concern Scales (Templer, 1970; Dickstein, 1972)

These scales have previously been used in America on populations of funeral directors and so are of interest to make cross cultural comparisons and also to compare funeral directors who are working in disaster situations with those who are not.

Section 4: Work and coping strategies.

Work Orientation (Crouch, 1975) Again this scale has been used on an American population of funeral directors. It is of interest here to compare the work orientation of those working as funeral directors as part of the every day business and those who are engaged in disaster work to see if any differences are apparent.

A likert scale of different aspects of the work will be rated by the funeral directors these included:

Enjoyable aspects of work

Stress of working with families in different types of deaths

Stress of body work in different types of deaths

Support Networks have previously been examined amongst emergency workers (McCammon *et al*, 1988) but have excluded funeral directors. It has been

included in this piece of research to add to the research both on disaster workers and on funeral directors.

Coping Inventory (Folkman and Lazarus, 1985) Is the one of most often used ways of coping inventories and was felt to be the most appropriate to use on this population because of the breadth of responses.

Design and Procedure

It is proposed that both descriptive and comparative statistics will be used to do the following:

- 1- Provide a description of the population demographically and in terms of health and mood.
- 2- Provide descriptive data concerning levels of death anxiety and concern to compare with information from American funeral directors.
- 3- To determine the work attitudes and styles of coping used by the sample as a whole.
- 4- To compare those funeral directors who are involved in disaster work and those who are not on variables such as general health, mood, experience of PTSD and coping.

Data Analysis

The data from the study will be subject to statistical analysis using SPSS/PC+ at the Department of Psychological Medicine, University of Glasgow.

Purpose

The purpose is to provide a hitherto lacking quantitative description of this population with respect to psychological measures, and to determine the use and style of coping methods in this group. It is hoped that the results of this research

will provide an insight into this population in terms of their response to and coping with death and may guide others in the optimising of coping resources.

Timescales

It is proposed that the project will commence in February 1994 and that data collection will be completed by September 1994. The final report will be presented in August 1995.

Ethical Approval

Ethical approval has not been directly required by the National Association of Funeral Directors. The research proposal has been presented to, discussed with and approved by both the contact funeral directors and the district associations or companies they represent.

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SECTION 3: MAJOR RESEARCH PROJECT PAPER

Funeral Directors: Hidden Victims or Copers?

Prepared in accordance with guidelines from:

MORTALITY
(appendix 1)

FUNERAL DIRECTORS: HIDDEN VICTIMS OR COPERS?

abbreviated title: Funeral directors and coping

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FUNERAL DIRECTORS: HIDDEN VICTIMS OR COPERS?

ABSTRACT

The focus of this research is the quantitative description of funeral directors in terms of: general health and mood; attitudes towards death; and, work and coping strategies. Within this investigation comparisons were made of those who are and those who are not involved in disaster work. The results show that the whole sample had low anxiety and concern regarding death. Symptoms of psychological distress were more evident in those not involved in disaster work. Whereas those who were involved in disaster work showed lower levels of psychological distress, more effective coping, and work practices which are in keeping with recommendations of previous researchers.

FUNERAL DIRECTORS: HIDDEN VICTIMS OR COPERS?

INTRODUCTION

Post Traumatic Stress Disorder (PTSD) has been officially recognised as a mental disorder since 1980 (American Psychiatric Association (APA), 1980). The criteria has recently been updated (DSM-IV, 1994) to include 'witnessing death, serious injury or the aftermath of injuries as triggers'. Most notably with respect to this piece of research is the inclusion of proximity to dead bodies or body parts.

The last decade has seen an appreciable increase in the amount of research dedicated to this disorder. The frequency and graphic level of reporting of disasters (both man made and natural) also appears to have increased with those involved at the site having been described both as heroes and victims (Paton, 1989; and Kliman, 1976). It would appear that victim tends to be the case more often than hero (Wroblewska, 1995).

It is the exposure to dead bodies and body parts both within and outwith the disaster situation which is of interest in this piece of research. Three factors fuel this research. Firstly, Mitchell (1990) found that at the Lockerbie disaster mortuary duty was considered to be the worst job, and yet the experience of PTSD symptomatology amongst workers was inversely related to the time spent in the mortuary i.e. the more time spent in the mortuary the fewer the symptoms. Secondly, Brooks and McKinlay (1992) found that proximity to body parts in Lockerbie was significant in the development of PTSD in rescue workers. Thirdly, the aforementioned broadening of the DSM-IV criteria. These developments support well founded evidence in animal studies which report the phenomenon of fear and flight when exposed to mutilated members of one's own species (Lawick-Goodall, 1968, Harlow; 1959, 1961, 1965), and the occurrence of habituation as a result of repeated exposure to a stimulus (Dickinson, 1980).

So far, then, the research has focused upon the experience of PTSD, and little attention has been given to the relevance of triggers (such as deathwork) to the development of, and the protection from, clinical symptoms of anxiety and PTSD proper.

Developed countries are now more insulated than ever from the experience of death. Furthermore our exposure to death and dead bodies has changed over the years: it is rare to see real death and when it is seen it is frequently accompanied with a sense of injustice (Wroblewska, 1995). The funeral director, however, remains the one professional for whom deathwork is the daily routine. More recently we have seen the emergence of funeral directors who work at disaster sites, identifying, reconstructing and embalming bodies before repatriation. (see appendix 2 for a full explanation of the work of Kenyons Emergency Services (KES). Also the quotes from 006 and 05 (see appendix 3) provide examples of the work, experience and feelings of KES workers).

The use of coping strategies may provide information regarding the experience of PTSD, disasters, and the work of funeral directors. How funeral directors cope with their work has been considered sociologically and styles include: taking a scientific view of their work (Thompson 1991); focusing on the business aspects of the job (Reynolds and Kalish (1974); suspension of society's preconceived notions about deathwork and the construction of new moralities (Howarth, forthcoming). Quantitative examination of this population has not been considered and may provide an insight into the funeral directing profession, the results of which could be of use to other workers in disaster situations.

Thus the aims of this piece of research are: to describe this population psychologically; and, to determine if and how they cope with deathwork. Also of interest is whether or not those engaged in disaster work experience any more difficulties or cope differently from the norm.

METHOD

Subjects took part in the study on a self-selecting basis after being contacted personally by one of two sources: either the Strathclyde regional representative of the National Association of Funeral Directors (NAFD), or by the co-ordinator of KES. A total of 23 funeral directors (one also a forensic pathologist) took part in the study. Of these 21 were men and two were women. The mean age was 40 with a range between 23 and 67 years. Eighteen of the subjects were married, four were single and one was remarried, Eleven had children and 12 had no children.

In this main sample there was a sub-sample of six funeral directors who are working currently for KES, and as a result were 'on call' to attend any disaster scenes. A further two had been involved in disaster work but it was not clear if this was under the auspices of KES. The KES workers were all based in England, except one, the rest of the sample were all Scotland based. This profession tends to be very wary of interpretive research and public scrutiny so the sample being self-selected may have some bearing upon those involved and the answers given.

Procedure

Funeral directors opted to be involved in the study after receiving a letter explaining its aims (see appendix 2, section 2). This was sent either by the NAFD representative for Strathclyde or the KES co-ordinator. If they agreed to be involved a consent form (appendix 3, section 2) was returned and a questionnaire (appendix 4, section 2) was dispatched to them. The return rate for the questionnaire was 88%.

Measures

Section 1: You and Your Background

General background and demographic data

Section 2: Questions About Health and Mood

General Health Questionnaire (Goldberg, 1978)

Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)

PENN Inventory (Hammarberg, 1992)

Section 3: Attitudes to Death

Templer Death Anxiety Scale (Templer, 1970)

Dickstein Death Concern Scale (Dickstein, 1972)

Section 4: Work and Coping Strategies

Crouch Work Orientation Scale (Crouch, 1975)

Likert scales on:

Aspects of enjoyment at work

Stress of working with families

Stress of working with bodies

Rating of Support Networks (McCammon *et al*, 1988)

Coping Inventory (Folkman and Lazarus, 1985)

RESULTS

Section 1: Background Data

The average number of years spent by subjects as a funeral director was 16 ranging from a minimum of three to a maximum of 45. Training could be roughly categorized into three types either: formal, i.e. completion of NAFD approved exams in funeral directing and embalming (n=10); informal, i.e. being trained by a family firm or joined and trained by a firm 'in house' (n=5); or, a mixture of both formal and informal (n=7). Data was missing for one subject. Two out of the 23 stated that they were trained regarding bereavement counselling but the type of training was not explained further.

Table 1

Natural deaths and deaths by accident are the most frequent types dealt with by the sample. How those members of the sample who are involved in disaster work (n=8) have chosen to classify the deaths they deal with is not always consistent, and as a result the data may not be accurately representative and should be considered a rough picture of the type of work done.

Twelve of the funeral directors had relatives who were also involved in the profession. Eleven were the only member of their family who were involved in the funeral directing profession.

Beyond the descriptive data further comparative analyses were carried out (independent samples t-tests) to determine if those involved in disaster work differed in any respect. Of the whole sample eight had been involved in disaster work and the remaining 15 were doing regular funeral directing type work without any experience of major disaster situations.

Section 2: Health and Mood

Table 2

In all areas except depression the majority of the subjects showed levels of somatic symptoms, anxiety and insomnia, and social dysfunction which was on or above the threshold for caseness.

Those who *had not* been involved in disaster work experienced more somatic symptoms ($p=.06$) and more anxiety and insomnia symptoms ($p=.03$) as measured on the GHQ.

Table 3

As with the GHQ features of depression were not reported by many of the sample. Symptoms of anxiety, however, were reported by nine of the subjects.

Those who *had not* been involved in disaster work experienced greater levels of caseness on the HAD anxiety scale ($p = .02$).

Table 4

Only three subjects reported severe enough symptoms to warrant a level of caseness of PTSD using the PENN Inventory.

Section 3: Attitudes to Death

Table 5

These results show that the data from this sample concerning death anxiety is in keeping with that obtained abroad i.e. that death anxiety is low and lower than that of the general population.

Data from the Death Concern Scale yielded a mean of 59.70 and a standard deviation of 9.72. This is in keeping with Dickstein's (1972) low death concern group where the mean = 59.81 and the standard deviation = 6.39. Again this data shows that this population has low concern for death.

Section 4: Work and Coping Strategies

Table 6

Those who are involved in disaster work feel it is more important to have the opportunity to work with people rather than things ($p=.006$).

The Likert scale looking at 'enjoyable aspects of work' found that all of the aspects mentioned were reported to be largely enjoyed by the funeral directors (see appendix 4). Those who *had* been involved in disaster work were found to report enjoying both working with the bereaved family and the business and

professional side of their duties ($p=.04$ for each) significantly more.

The second Likert scale looking at 'the stress of working with families' in different types of deaths showed that natural deaths were reported to be unstressful, and that suicides, murders and childhood deaths tended towards the stressful end of the scale. Accidental deaths had a broad spread across the scale and this may be due to the differing experiences in accidental deaths of the funeral directors involved in disaster work and those not. (See appendix 5). Disaster workers did not differ in this respect.

On the third Likert scale 'working with the body' natural deaths were reported to be least stressful, stress from the other sorts of body-work spread evenly amongst the rating, although it is interesting to note that the answers were often at one or other extreme (see appendix 6). Disaster workers did not differ in this respect.

Ratings of support networks were found to be similar to the findings of McCammon *et al* (1988) i.e. that support tended to come primarily from family, colleagues. (see appendices 7).

Table 7

In the coping scale the following significant results were found.

Those *not* involved in disaster work were *more likely* to:

hope for miracles ($p=.007$)

accept sympathy and understanding ($p=.001$)

try and forget the whole thing ($p=.03$)

get professional help ($p=.01$)

be apologetic or try to do something to make up ($p=.001$)

feel they had brought the problem on themselves ($p=.03$)

turn to work or some substitute activity ($p=.008$)

try and change something so that things would turn out alright ($p=.004$)

think that time would make a difference (p=.05)

avoid people (p=.03)

talk to someone about how they were feeling (p=.01)

take it out on others (p=.04)

bargain or compromise to get something positive out of the situation (p=.02)

talk to some one to find out more about the situation (p=.007)

be critical of themselves (p=.005).

They were *less likely* to feel that they have come out of the experience better than they went in (p=.01)

DISCUSSION

In this sample of funeral directors there are two distinct groups: those who work in normal firms; and, a smaller proportion who have been involved in disaster work. Both are considered representative of their profession and experiences. Formal training according to the NAFD regulations tends to be the norm.

In this piece of research those funeral directors not involved in disaster work were found to be more likely to show levels of caseness in the anxiety and insomnia and somatic symptoms domains of the GHQ, and the anxiety scale of the HAD. This is in keeping with previous findings made by Mitchell *et al* (1991) on emergency service workers. The suggestion then, is that funeral directors not involved in disaster work are psychologically in keeping with other workers in a stressful situation. It is tempting to assume that the level of symptomatology is attributable to the stress of death and bodywork, and not to any extraneous variables. However, the qualitative data given by the funeral directors suggests a possible unconsidered alternative reason for their anxiety, (see appendix 3 for quotes from 004, 014, 016, and 020) and certainly the majority of the sample were not anxious to a level to indicate PTSD as measured on the PENN inventory.

Habenstein (1962) suggested that the funeral director's constant striving to meet the needs and expectations of the families can lead to stress and strain. It may be that families are more demanding in the non-disaster situation whereas in the disaster situation a positive identification and repatriation of the body is satisfying enough. As a result there may be less stress placed upon the funeral director working in a disaster situation. At KES the occasional experience has been described wherein a link has been established between the home team and the family. Here the funeral director involved goes on to make the funeral arrangements or to liaise with the firm involved. Further investigation needs to be done to clarify this issue. The finding of high social dysfunction in this sample is not unexpected given the social stigma of the profession.

Death anxiety and concern is consistently low which is in keeping with previous research (Templer and Ruff, 1971; Pepitone-Arreola-Rockwell, 1981; and Schell and Zinger, 1984). The interpretation that could be made here is that issues concerning death have been incorporated into their morality. Howarth (forthcoming) describes this as a form of coping. Horowitz (1980) suggests that our assumptive world changes as a result of traumatic events and that we integrate these events into new altered models of the world. It may be the case that funeral directors have a different model for death which incorporates their increased experience and so anxiety and concern is manifestly lower. This may be aided by the process of self-selection into the profession whereby those who are unable to reconstruct their world appropriately either elect not to be involved in the profession in the first place or leave the job. Howarth (forthcoming) discusses this process in depth.

In this sample the mean scores for each item on Crouch's work orientation scale were calculated (see Table 6). Of the factors Crouch identified (1975) statements reflecting 'concern to people', and 'professional/community issues' were consistently rated highest by the whole sample. 'Business and career issues' were felt the least important. It is of interest to note that the mean for the sample on two statements was below the mean on the scoring schedule (1.5), 'making a

good deal of money' and 'being a good salesman', these items being in the 'business and career issues factor'. Those who were involved in disaster work felt it to be more important to have the opportunity to work with people rather than with things, which falls into the 'concern for people' factor. The importance placed upon this aspect of their work may indicate why they go into disaster work, or may be something which results from their involvement in disaster situations and the help they have provided. Certainly the satisfaction at having done a job well and a family being able to view a body is often described. (see appendix 3 for quotes 001 and 004).

The Likert scales looking at enjoyable and stressful aspects of funeral and body work found that all aspects of funeral work were enjoyed. Those funeral directors involved in disaster work enjoyed working with the bereaved family and the business and professional side of their work significantly more. This is in keeping with the finding that they feel it more important to work with people rather than with things. As already explained the set up at KES is such that the home team have a close liaison with the family, both parties striving for a mutual goal of identifying and repatriating the body (see appendix 2). It would be of further interest in the future to look at the differing experiences of the members of the home and site teams after an incident. As with previous research on other populations (Dyregov and Mitchell, 1992) and as reflected in the qualitative data, childhood deaths proved to be the most stressful (see appendix 3 for quotes 005, 013, 021).

Social support was used consistently by the sample in much the same way as other emergency service workers looked at by McCammon *et al* (1988). Family and colleagues provided most support.

In this piece of research the methods of coping most often used by all of the funeral directors follow those described by Folkman and Lazarus (1986) as 'planful problem solving' and 'positive re-appraisal'. Those least used were the 'escape-avoidance' type. Comparative statistics found that the strategies could be

differentiated according to whether disaster work was done or not. Those not involved in disaster work tended to use methods of 'seeking social support', 'accepting responsibility', 'escape-avoidance' and 'distancing'. Those who were involved in disaster work used 'planful problem solving' and 'positive re-appraisal' more frequently.

Funeral directors who specialise in disaster work differ from other emergency service workers in their approach to their work and often use techniques which have previously been found to be effective in disaster situations (see appendix 2). They tend to prepare for and have an accurate interpretation of and information from the site before entering it (Paton, 1992). The organisational support is well defined and operated (Paton, 1992; Stuhlmiller, 1994). Group and team building, peer and individual support is available (Paton, 1990). The preparation for the work is both realistic and practical (Horowitz *et al*, 1980). Their role is clearly defined (Stuhlmiller, 1994; McCammon *et al*, 1988; Paton, 1990). Tools are appropriate to the work (McCammon *et al*, 1988). Debriefing is standard at the end of an operation (Dyregov, 1989).

The findings of this piece of research has shed light upon the experience of funeral directors in the contexts of their everyday work and as disaster workers. The notion of death and the sight of bodies is not reported to be upsetting to the sample as a whole thus supporting the theories of 'self dosing' (Horowitz, 1980) and habituation (Dickinson 1980). This may be an effective buffer against PTSD being triggered by exposure to dead bodies and body parts in disaster situations. Stuhlmiller (1994) suggested that the work of coroners at a disaster site was in keeping with their normal work and therefore they could continue to work effectively. The same appears true for funeral directors. 'Planful problem solving' and 'positive re-appraisal' are more effective forms of coping and this is reflected in the finding that those who used these methods, namely those involved in disaster work, did not report high levels of psychological distress. Those funeral directors who are involved in disaster work appear to have a well structured and professional approach. This supports the findings of previous research on disaster

and emergency service workers and provides an example of how the use of effective working practices and coping strategies can maintain psychological wellbeing. Beyond this, effective approaches may act to resolve previous difficulties or indeed to help prepare the individual to pre-empt dysfunctional responses in future traumatic situations.

Table 1: The types deaths being seen by these funeral directors as a whole group.

TYPE OF DEATH	mean	min	max	n
Natural	205	0	500	21
Accidental	37	0	280	21
Suicides	3.5	0	20	21
Murders	1.1	0	5	21
Children	2.4	0	6	21

Table 2: Distribution of GHQ scores.

GENERAL HEALTH QUESTIONNAIRE (n=23)			
	< 4	4/5	> 5
Somatic Symptoms	10	5	8
Anxiety and Insomnia	8	6	9
Social Dysfunction	1	6	16
Depression	20	1	2
coding=0123, threshold=4/5			

Table 3: Distribution of HAD scores

HOSPITAL ANXIETY AND DEPRESSION SCALE (n=22)	< 8	8-10	10+
Anxiety	13	5	4
Depression	20	1	1
threshold=8/10			

Table 4: Distribution of PTSD scores.

PENN INVENTORY (n=23)	< 35	> 35
threshold=35	20	3

Table 5: Data from previous and current studies using the death anxiety scale.

AUTHOR	n	mean	sd
Templer and Ruff 1971	3600+ (non funeral directors)	7.30	7.75
Pepitone-Arreola- Rockwell 1981	28 (funeral directors)	4.43	3.17
Schell and Zinger 1984	149 (funeral directors)	6.08	2.73
present paper	23 (funeral directors)	4.70	2.55

Table 6: Table showing, in descending order, the mean distribution of work orientation statements.

Work Orientation Statements	mean
1. Autonomy in my work; having the freedom and responsibility to do the job in the way I feel it should be done.	2.826
2. The chance to help people; to do something worthwhile for society.	2.609
3. The opportunity to work with people rather than with things.	2.478
4. Continually advancing the knowledge and the skills through reading and formal courses.	2.348
4. Working with people who are committed to funeral service as a life career.	2.348
6. Being respected as a good businessman.	2.304
7. Successfully managing the commercial affairs of the mortuary.	2.130
8. Close contact with other funeral directors around the region and country.	2.087
9. Attending funeral association meetings.	1.957
10. Reading funeral service literature.	1.870
11. Moving up within this funeral establishment.	1.826
12. Social status and prestige in the community.	1.739
13. Making a good deal of money.	1.435
14. Being a good salesman.	1.087

Table 7: Table of most and least used coping strategies

Most Used Methods of Coping	Mean Score	Least Used Methods of Coping	Mean Score
1. Just concentrate on what I had to do next-the next step	2.22	1. Refused to believe what had happened	0.130
2. I knew what had to be done, so I doubled my efforts to get things done	2.174	2. I got professional help	0.304
3. I tried to keep my feelings to myself	1.957	3. Slept more than usual	0.391
4. I tried to analyze the problem in order to understand it better	1.913	3. Took a big chance or did something risky	0.391
5. I tried to see things from the other person's point of view	1.826	5. Found new faith	0.435
6. Rediscovered what is important in life	1.783	5. Hoped a miracle would happen	0.435
7. Tried to talk to someone to find out more about the situation	1.739	7. Went along with fate; sometimes I just have bad luck	0.522
8. Drew on my past experience; I was in a similar situation before	1.696	8. Avoided being with people in general	0.565
9. I reminded myself how much worse things could be	1.652	9. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication etc	0.609
10. I came out of the experience better than I went in	1.565	10. I accepted the next best thing to what I wanted	0.652

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SECTION 4: SMALL SCALE EVALUATION PROJECT

Women's Knowledge of Pre-natal Screening

Prepared in accordance with the guidelines from:

THE JOURNAL OF REPRODUCTIVE AND INFANT PSYCHOLOGY
(appendix 1)

WOMEN'S KNOWLEDGE OF PRE-NATAL SCREENING

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WOMEN'S KNOWLEDGE OF PRE-NATAL SCREENING

ABSTRACT

In recent years with the introduction and increasingly widespread use of pre-natal testing and screening an increased focus has been placed upon women's knowledge and the notion of informed consent. The general finding is that women are not always well informed. Following on from the research of Marteau *et al* (1988) and Green *et al* (1993a) this study explores the knowledge of 100 women attending the maternity hospital in Glasgow responsible for the introduction of pre-natal screening in Scotland. The women were surveyed directly after having had the alpha-fetoprotein blood test to consider both their knowledge and their views concerning the Royal College of Obstetricians and Gynaecologists guidelines. Overall knowledge was found to be good in relation to the practicalities of screening but not in terms of the implications. Women felt that the RCOG guidelines were adhered to. Recommendations were made to change and improve the service.

INTRODUCTION

The serum alpha-fetoprotein (AFP) screening test (i.e. screening for the presence of biochemical markers of neural tube defects such as spina bifida) was first introduced in the 1970's. To take part in this women have to give 'informed consent'. Blumberg (1975) suggests that 'An intelligent decision requires the input of all the available data, and that ignorance of the psychological aspects of selective abortion precludes a fully informed decision'. Since the introduction of testing for Down's syndrome the age for testing has steadily decreased from 45 year olds who have a 1:15 chance to 35 year old's who have a 1:350 chance of an abnormal result (Tymstra, 1991). With the advance of technology and the increasing desire to have a 'perfect' child screening and testing is no longer

reserved for those at risk of having an abnormal baby. Most hospitals do not now restrict screening. Richards and Green (1993) suggest that screening has such a high uptake because it is offered as part of a 'reassuring package of ante-natal care'. With this increase in usage there is a concurrent increasing concern in the manner in which screening is presented to women and how much knowledge they have before embarking upon the procedure and its possible consequences. As a result, over the last decade there has been an increase in the amount of research devoted to this area, and the Royal College of Obstetricians and Gynaecologists (RCOG, 1993) have set guidelines as to the administration of both the test and pre and post-test counselling. In terms of the psychosocial effects of screening Berne-Fromell (1982) found increased anxiety amongst women which can be alleviated by adequate medical information and reasonable psychological support. He also found that anxiety in women who had been screened was less than in those who had not been screened.

Over the last 10 years research has shown the following:

Midwives knowledge is incomplete and they are unable to handle the anxieties of the mothers (Sanden, 1985).

Knowledge needs to be clear in two areas, the commonality of malformations and the specificity of the test (Sanden, 1985).

Faden *et al* (1985) found that simply participating in screening increased the level of knowledge. As for the reading matter distributed, 86% reported reading the pamphlet and only 40% reported discussing the test with their doctor.

In terms of how screening is presented Marteau *et al* (1992) found that although screening is discussed quite openly little is actually mentioned regarding the test itself, what it screens for and the meaning of positive and negative results. Again it was found that poor knowledge is related to poor information giving. Staff's explanations were brief and they suggested that this may be due to a number of factors including; lack of knowledge, attitudes or presentation skills. Information tends to be disseminated by leaflet rather than face to face.

In discussing screening Marteau (1993) found that risk tends to be discussed in terms of likelihood rather than the risk of having an affected child. Information regarding the conditions being tested for was unclear and poor knowledge again seemed to be related to the level of the staff's knowledge. Marteau argues that amongst this we need to consider the attitudes of the staff towards screening and termination, and their feelings about discussing such issues. Information is not compatible with informed consent at present she concludes.

Green *et al* (1993a) suggest that increased knowledge results from talking to peers in the community and that some of the confusion arises as a result of different language being used. They found that age, education level, occupation and hospital policy all affected the level of knowledge.

Smith *et al* (1994) found that although women were informed about the practical aspects of the test and its outcome, they were less well informed about the implications of the test outcome which does not comply with the RCOG (1993) guidelines. A lot of women consider the test a form of reassurance that all is 'OK', and not that the result may mean the consideration of termination (Green *et al*, 1993b).

Other aspects of research in this area beyond client knowledge include; the psychological effects of false positives and negatives, and retrospective data collected from women who have had terminations as a consequence of the test results (Marteau, 1993; Stratham and Green, 1993; Roelofsen *et al*, 1993; Jørgensen *et al*, 1985; Leschot *et al*, 1982). Counselling pre and post-testing is under much more consideration. Green (1994) found that in their sample all obstetricians were offering pre-natal screening, and that nearly half of the sample reported that they did not have adequate resources to offer counselling.

The above shows the development of the research from the initial suggestion that women's knowledge about the actual test and what it screens for, is poor to more recent research which combines this with considerations of the implications of

the test and what is to be done next. Overall most women want to take the test but they need to be better informed and not just told to go home and not worry (Stratham and Green, 1993).

Yorkhill NHS Trust Hospital provides pre-natal screening for all women and has been included in the RCOG guidelines as an example of good practice. Their information sheet is also being presented as a guideline for what should be included. Staff, however, are not convinced of this status and are often confronted by women who have had a positive AFP result and are presenting for ultrasound tests unclear as to why they were to attend and the nature of the procedure they were about to undertake and its implications. As a result staff have asked for an audit of their service to be done in order to determine the knowledge of the women at the time of undergoing AFP screening, and how this corresponds to the RCOG guidelines.

METHODS

Hospital screening policy.

The hospital's current procedure is to give women an information leaflet on AFP screening (appendix 2) when they attend their first 'booking in' appointment. After this they then attend for pre-natal screening at some time between 15 and 21 weeks into the pregnancy. The AFP blood test is taken and they are informed of the results by post two weeks later. One of three types of letter are then dispatched: either letter 1 to inform that they are in the low risk group and no further action need be taken, (appendix 3); or letter 2 to inform that they have received a high AFP result and that the hospital would like to perform an ultrasound scan (appendix 4); or letter 3 that they have a low AFP result and that an appointment has been made for them at the hospital when they can discuss this result further (appendix 5).

Subjects.

For this audit 100 women were asked to complete a questionnaire (appendix 6)

after they had seen the midwife for their blood test. In this way it was hoped that knowledge and relevant issues would be fresh in their mind. The questionnaire was distributed by a consultant and the author. Midwives were aware that the study was taking place but were unaware of the actual contents of the questionnaire.

The questionnaire.

The questionnaire included three sections. Section one sought basic demographic information about the woman and where she had received information regarding pre-natal screening. Section two adapted Marteau *et al*'s (1988) knowledge questionnaire to reflect changes in practice and policy in this hospital. This is more in keeping with the adaptation made by Green *et al* (1993a) who broadened the number of responses available so that an indication could be gained of the mis-conceptions as well as the correct knowledge. In section three questions were asked regarding the RCOG guidelines to determine whether women felt that they had been complied with or not. The women were given the opportunity to discuss any of the questions and to raise any queries they may have after they had completed the questionnaire.

RESULTS

Analysis.

Using the Statistics Package for the Social Sciences (SPSS) analysis has focused upon providing general distributions of the samples answers.

Sample Characteristics.

The age range of the sample was between 16 and 40 years with a mean age of 28 years. Fifty percent of the sample had at least one previous child and for 41% of these the child was born at the hospital where the study was carried out.

Therefore it could be assumed that they have previously had antenatal care similar to the current pregnancy. All of the women were between week's 15 and 17 of their pregnancy. Women were asked if they had had any form of serum

screening thus far in this pregnancy. As this questionnaire was distributed *after* serum screening had taken place one would expect that all of the women would answer in the affirmative to this question. However, 35% of the sample answered no and 15% of the women were unsure. As to whether they have had serum screening previously, 37% of the sample reported yes, 42% reported no and 17% were unsure (4 missing cases).

Sources of information prior to screening.

Table 1.

Table 1 shows that the majority of women (75%) are using the leaflet from the hospital as their main source of information. Sixty percent are informed by the hospital staff. Twenty seven percent were using only these two sources. Interestingly quite a number of women are using more informal sources of information such as talking with other women (18%) and books and magazines (19%). Most women are using two different means of gaining knowledge (38%).

The Knowledge questionnaire.

Table 2.

* Refers to the correct answers, in the case of amniocentesis and CVS this is assuming all is well with the pregnancy

Like Marteau *et al* (1988) and Green *et al* (1993a), most women expected to have urine tests, blood tests, blood pressure checks, scans and ultrasound during their pregnancy. A smaller proportion (59% and 58% respectively) expected tests for spina bifida and Downs syndrome. This being directly after having had precisely these tests. There was a spread of expectations regarding amniocentesis with 18% expecting the test. Finally regarding chorionic villus sampling (CVS) the majority of women (35%) reported not having heard of the test and a further

20% simply answered 'don't know' to the question.

Tables 3-11 show the answers given to the individual knowledge items of the questionnaire. The correct answers are highlighted in bold. It should be taken into account that women completed this questionnaire directly *after* having the AFP test during which the procedure, results and implications are explained and discussed by the clinic staff. Therefore the expectation is that knowledge would be at its best, if not perfect.

Table 3.

The majority of the women got the correct answer, that this hospital provides testing for all women. Other hospitals restrict their testing to women with a history of spina bifida, so it could be argued that women who gave that answer were also to some extent correct. Just over a quarter of the sample suggested that older women are routinely tested which is not the case.

Table 4.

The majority of the women got the correct answer, that this hospital provides testing for all women. Other hospitals restrict their testing to women with a history of Down's syndrome and older women so it could be argued that women who gave these answers were also correct.

Table 5.

In answer to this question the majority of women (81%) got the correct answer in combination with other answers. Nearly half got the correct answer alone.

Table 6.

Very few of the women got the two correct answers alone (3%). Seventy-nine

percent of the women had one or both of the answers in combination with other answers. However 76% of the women got wrong answers either alone or in combination with other answers.

Table 7.

The answers to this question show a good knowledge of the purpose of amniocentesis with the majority of women selecting one or other of the correct answers. Almost a third of the sample got both answers correct alone.

Table 8.

The majority of the women in the sample (63%) reported not knowing the function of the CVS test. A significant proportion of the sample (25%) indicated the correct answer and only 18% got the single answer correct.

Table 9.

Nearly 50% of the women in the sample indicated to two correct answers alone for this question. Also 'making sure the baby is alright' and 'to look for abnormalities' were the most often indicated answers (69% and 82% respectively).

Table 10.

The majority of the women in the sample were completely correct in their answer to this question.

Table 11.

Although the majority of the sample (61%) indicated spina bifida as the answer to this question and 26% and 16% indicated the other correct answers, only 4%

of the sample got all three answers alone correct. Interestingly nearly half of the sample indicated that they thought the raised result would indicate Down's syndrome, also a quarter of the sample indicated that they did not know the answer to this question.

The RCOG Guidelines.

Table 12.

The results of these questions would suggest that overall women feel that the guidelines have been adhered to. Where the women feel that guidelines have not been followed concerns options after the test and how to get more information if needed.

DISCUSSION

This audit has been designed to look at two issues specifically. Firstly, it considers women's knowledge regarding serum screening at the time of the test, when knowledge should be at its best. Secondly, it considers women's opinions whether the RCOG guidelines concerning screening have been adhered to up to and including the test.

One of the main findings of this audit has been that the majority of the women taking part use either the leaflet given at the 'booking in' visit, or gain knowledge by talking to the hospital doctor or midwife as their main source of information. This coincides with Faden's (1985) finding of 85% reporting to reading the hospital pamphlet. The leaflet, therefore, would appear to be the main source of information and as such its contents and presentation is of great importance to ensure 'informed consent' to pre-natal screening. Green *et al* (1993a) have suggested that knowledge may, to some extent, be due to women

talking with peers. This audit has found that this indeed is the case; a significant proportion of the sample used both peers and general literature as a source of information. As a result there may be a confusion in terminology used from these different sources, an issue which requires explanation to women.

Overall the women's knowledge at the time of screening is reasonably good. There are, however, some gaps. The majority of the women expected to receive the general tests of urine, blood, blood pressure and ultrasound. Of concern is the finding that only a fraction over half of the women were expecting the tests for Down's syndrome and spina bifida - the very tests they had just undergone! It has been suggested (Richards and Green, 1993 and Green *et al*, 1993b) that women interpret screening as part of the 'reassuring package of care' or as 'confirming that nothing is wrong'. This audit has shown that women interpret the aim of ultrasound as such, and it could be argued that this is also the view of the women in the case of serum screening.

Previous studies have found that knowledge is good for the practical aspects of serum screening, but not for the outcome and implications of the test (Roelofsen, 1993; Smith *et al*, 1994). This is also the outcome of this audit. The women know who is tested for what and when, also what amniocentesis and ultrasound are for. Where there appears to be a lack of understanding, however, is with respect to the consequences of abnormal results, what CVS is, and the meaning of a raised AFP.

Although women report that the RCOG guidelines have been complied with, their knowledge concerning the meaning of results and their implications do not back this up. Most concerning is the number who report that the options after the test were not discussed, or that they were not told how to get any more information should they want it.

The following recommendations are therefore made as a result of this audit:

- 1- The leaflet given to women should be updated to include information regarding CVS and clearer details regarding the meaning of test results and who should be contacted for further information.
- 2- The leaflet should to some extent explain all the different terminology used to try to reduce confusion at the outset.
- 3- Whilst the AFP test is being done, and women are in consultation with the midwives, the use of a prompt card such as that shown in the RCOG guidelines (p.40) may be of use in ensuring the level and quality of information given to women.
- 4- No matter how short the time is between receiving the letter from the hospital and the follow-up appointment for further testing, a woman's anxiety will be raised. The letters which are currently sent out by the department are too vague (appendices 3, 4 and 5). It may be this factor which is leading to the staff experience of women attending for further tests unsure as to why it is required. As Berne-Fromell (1982) has shown increased information and support alleviates anxiety and confusion. It is suggested, therefore, that after the test women are given another short leaflet to explain what happens next and what it means. This could be done in the form of an easy to follow flow chart (appendix 7).

Table 1: Percentage of women using different sources of information prior to serum screening.

Leaflet from hospital	75%
Talking with doctor/midwife	60%
Talking with GP	8%
Talking with other women	18%
Books and magazines	19%
None	1%

Table 2: Percentages of women who heard of and/or expected certain tests during pregnancy.

Tests	Heard of (%)	Not heard of (%)	Expect it (%)	Don't expect it (%)	Don't know (%)
Urine	28	2	70*		
Blood	29	1	70*		
Blood pressure check	28	1	71*		
Scans/Ultrasound	29	1	70*		
Tests for spina bifida	37	2	59*		
Tests for Down's syndrome	38	1	58*	1	2
Amniocentesis	54	4	18	16*	6
CVS	20	35	3	11*	20

Table 3: ‘Who is routinely offered screening for spina bifida?’
 Percentages choosing each answer (correct answers in bold).

answer	%
Women with a history of spina bifida	23
Older women	27
All pregnant women	80
Don't know	0
63% answered ‘all pregnant women’ alone	

Table 4: 'Who is routinely offered screening for Down's syndrome?'

answer	%
Women with a history of Down's syndrome	34
Older women	36
All pregnant women	72
Don't know	1
59% answered 'all pregnant women' alone	

Table 5: ‘If screening for spina bifida gives an abnormal result what would be likely to happen next?’

answer	%
Another scan would be arranged	81
Amniocentesis would be offered	32
CVS would be offered	8
The baby would be treated soon after birth	3
Termination of the pregnancy would be offered as an option	22
Don't know	4
49% answered ‘Another scan would be arranged’	

Table 6: 'If screening for Down's syndrome gives an abnormal result what would be likely to happen next?'

answer	%
Another scan would be arranged	47
Amniocentesis would be offered	64
CVS would be offered	15
Termination of the pregnancy would be offered as an option	24
Don't know	5
3% answered 'amniocentesis would be offered as an option' and 'CVS would be offered' alone	

Table 7: 'Amniocentesis is used to test for?'

answer	%
Diabetes	2
Down's syndrome	83
Spina bifida	43
Cerebral palsy	2
Don't know	7
31% answered 'Down's syndrome' and 'spina bifida' alone	

Table 8: 'CVS is used to test for?'

answer	%
Diabetes	0
Down's syndrome	25
Spina bifida	17
Cerebral palsy	3
Don't know	63
18% answered 'Down's syndrome alone'	

Table 9: ‘Apart from checking the age and growth of the baby what is the main use of ultrasound scans in pregnancy?’

answer	%
To make sure that the baby is alright	69
To see what sex the baby is	7
To test for blood disorders	1
To look for abnormalities	82
Don't know	0
45% answered ‘to make sure that the baby is alright’ and to look for abnormalities alone	

Table 10: 'During the pregnancy when are the main tests to see if the baby is likely to have spina bifida or Down's syndrome carried out?'

answer	%
Before 15 weeks	2
Between 15 and 21 weeks	95
Between 21 and 28 weeks	0
After 28 weeks	0
At any time in pregnancy	2
Don't know	1

Table 11: 'A raised AFP (alpha-fetoprotein) could mean?'

answer	%
Twins	26
Spina bifida	61
High blood pressure	3
Down's syndrome	46
Normal variation	16
Don't know	24
4% answered 'twins', 'spina bifida' and normal variation alone	

Table 12: RCOG guidelines and whether the clinic has complied with these guidelines according to the women receiving the service.

RCOG guidelines	YES (%)	NO (%)	UNSURE (%)	missing (%)
1. Were you told what screening was for?	97	3	0	0
2. Were you told the likelihood of Down's syndrome being detected?	70	19	11	0
3. Were you told how the screening would be done?	89	8	3	0
4. Were you told what a positive result means?	93	5	2	0
5. Were you told what a negative result means?	91	5	3	1
6. Were you told what will happen if the result is positive?	88	8	3	1
7. Were the options of what happens next after the test discussed?	72	25	3	0
8. Were you told how to get any more information if you wanted it?	60	34	6	0

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SECTION 5: SINGLE CLINICAL CASE RESEARCH STUDIES

The Effect of Self-Esteem on Social Phobia: A Case Report

The Cognitive-Behavioural Management of Prader-Willi Syndrome: A Case Report

The Effect of Childhood Memories on the Development of a Phobia: A Case Report

Prepared in accordance with the guidelines from:

BEHAVIOURAL AND COGNITIVE PSYCHOTHERAPY
(appendix 1)

THE EFFECT OF SELF-ESTEEM ON SOCIAL PHOBIA: A CASE REPORT

Abbreviated title: Self esteem and social phobia

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SUMMARY

The treatment of social phobia tends to be that of a cognitive-behavioural approach combining exposure techniques and cognitive reinterpretation. This report discusses the case of a 36 year old man who experienced a long standing history of a lack of self-confidence in social situations. Treatment focusing upon self-esteem issues to build self-confidence led to a marked improvement in attitude and behaviour.

INTRODUCTION

Phobias are special fears that are out of proportion to the demands of the situation, cannot be clearly explained, are beyond voluntary control and lead to an avoidance of the feared object or situation. Often there is a fear of the somatic sensations associated with anxiety. The patient is frightened of volatile physiology and panicking cognitions (Hawton, Salkovskis, Kirk and Clark, 1990). Social phobia includes difficulties with social situations and skills. Patients worry about being able to conceal their difficulties. Generally, the worst situation is to be highly visible to others e.g. speaking in public, walking into a room full of people and the presence of high status people. Individuals with social phobia have difficulties asserting themselves and tend to be over compliant.

In the treatment of phobias, exposure is considered to be the most effective approach (Emmelkamp, 1982). This has been established as the treatment of choice for simple phobias and agoraphobia, and latterly has been used in the treatment of social phobia (Butler, Cullington, Munby, Amies and Gelder, 1984). A cognitive based approach has been discussed by Last (1984). He suggests that cognitive therapy can be used as an adjunct to behavioural techniques with its primary function being to aid the development of appropriate interpretations. Applied relaxation and controlled breathing techniques can be appropriate to aid coping with the somatic component of anxiety during exposure (Ost, 1987).

Zilbergeld (1983) argues that self-esteem is positively affected as a by-product of therapy. This change in self-esteem often occurs due to a positive regard from the therapist and the fruitful experience of progressing through therapy. McKay and Fanning (1992), however, argue that this progress is often slow because self-esteem is usually addressed as a side issue and often in an 'inefficient and haphazard' way. As a result they have formulated a cognitive-behavioural approach which focuses specifically upon the recognition of self-criticism and a systematic approach to raising self-esteem.

In the literature on phobias in general and on social phobias in particular there does not appear to be any reference to self-esteem as a potential factor in influencing the

experience of an individual. It could be argued, however, that self-esteem is an integral part of social competence. It is suggested here, that in order for an individual to feel competent in a social situation they must first feel confident about themselves and their ability in that situation. It is with this in mind that this case is presented. Although treatment was not planned with self-esteem as the focus. It became apparent that by examining and improving self-esteem exposure to social situations also improved. This case report is therefore, intended to promote debate and encourage further examination of self-esteem exercises as a central focus of treatment.

CASE REPORT.

Mr G, aged 36 years, was referred with a 'long standing history of anxiety and lack of confidence'. Recently this had lead to difficulties in social situations. Mr G described having a marked sense of insecurity, and a lack of self confidence in social situations. This he argued had emerged over the last year due to excessive ruminations about his ability to be socially competent. When in a social situation he reported that he would experience a variety of symptoms including; shaking hands, churning stomach, flushing and profuse sweating. Those situations which caused most difficulty included: formal meetings at work; appointments relating to his work as a sales representative; meeting neighbours and conversations with women. These somatic signs of anxiety were accompanied by cognitions pertaining to other peoples perceptions of his performance in the aforementioned situations. e.g. 'will I be able to manage?', 'will people see?', 'will I loose my job because I am not competent enough?'

These thoughts and feelings were affecting his daily life to the extent that he would not make or keep appointments to meet clients at work or attend meetings. In situations outside work Mr G had stopped going out with friends or playing sport, and some simple activities of daily life were either deferred or not completed e.g. he was no longer taking the rubbish out in case he met any neighbours. Mr G reported that increased ruminations whilst he was alone had prompted the behaviour to escalate. As a result self-esteem and confidence had decreased and caused an increase in feelings of guilt and self-blame. He reported that his current method of coping was avoidance and

intermittent use of anxiolytic medication.

Mr G's presentation met the criteria for social phobia (code 300.22) as proposed in the third, revised edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1987). There were also some clinical signs of depression i.e. poor sleeping and low mood. However, these were not enough to warrant a secondary diagnosis.

Mr G had lived at his parental home up until approximately one year previously. He comes from a large family and was the second youngest of seven children. Mr G had lived alone since he left home. He reports having had some difficulties adjusting from living in a busy house to living alone and that living alone had provided him with more opportunity to ruminate on his abilities. Mr G is not currently involved in a sexual relationship but has been in the past, and did not feel that was an issue in his current problems. There is no psychiatric history in either Mr G or any other members of his family.

TREATMENT PROGRAMME

The treatment programme consisted of the following elements: education regarding the nature and physiology of anxiety, use of cognitive diaries and restructuring, self-esteem exercises and exposure *in vivo* without the use of a formal hierarchy, but rather leaving this as the responsibility of the patient.

At assessment Mr G completed the following questionnaires with the following scores:

The Hospital Anxiety and Depression Scale (HAD) (Zigmond and Snaith, 1983). Mr G's anxiety score equalled 15, indicative of caseness and depression score equalled 6.

The Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock, and Erbaugh, 1961). As the HAD does not cover the wide range of typical depressive symptomatology, Mr G was given a BDI. His score was 19, and indicative of mild

depression.

The Dysfunctional Attitude Scale (DAS) (Burns, 1980). Because Mr G was able to identify some of the core beliefs he held and was aware of their importance in his outlook the DAS was administered with the aim of both using it as a measure of Mr G's core value system and further as a therapeutic tool. Although not a formal measure of self-esteem the DAS does measure core beliefs i.e. the basic assumptions a person has about him/herself and the world. The following scores were obtained at the time of initial assessment. Negative scores are indicative of dysfunctional attitudes of increasing severity and zero and positive scores indicate increasingly functional attitudes.

-10 = the negative extreme and +10 = the positive extreme.

Approval	-5
Love	-8
Achievement	-1
Perfectionism	+3
Entitlement	-1
Omnipotence	+3
Autonomy	0

Treatment followed this format:

Session 1:

Formulation of the problem was fed back in a discursive manner to allow; comprehension of the development and maintenance of the problem, understanding of the aims and rationale of treatment, motivation and engagement in treatment to be gauged and encouraged if necessary. The patient was requested to keep a cognitive diary of anxious thoughts. The patient was also given a handout on understanding and the effects of anxiety.

Session 2:

The focus of this session was education regarding the nature and physiological effects of anxiety. This was done with particular emphasis on placing Mr G's experiences in the context of Clark's cognitive model of panic disorder (Hawton *et al*, 1990). Also in this session Mr G was instructed in relaxation and controlled breathing techniques.

Session 3:

In session 3 the emphasis was on the effect of negative cognitions and evaluations and their effects upon mood, motivation, confidence and most importantly self-esteem. Mr G's diary was then reviewed within this context, the therapist encouraging cognitive re-interpretations. The DAS was also discussed with Mr G identifying the dimensions embedded in the questionnaire and then considering what the consequences and behavioural expressions of certain assumptions may be. Mr G was very able to identify his own dysfunctional views and their resulting effects. He was given a further handout on cognitive restructuring of negative automatic thoughts and asked to review his diary, identifying thoughts and providing alternative explanations, for homework.

Session 4:

Mr G's diary was reviewed with an introduction to cognitive restructuring. The social situations he had attended during the week were also discussed in this context. The exercise on more accurate self-assessment, a self-esteem exercise (McKay and Fanning, 1987) was introduced in this session and the patient commenced the assessment and completed this as part of homework.

The exercise involves the patient listing adjectives and descriptions of themselves in the following eight dimensions: physical appearance; how you relate to others; personality; how others see you; performance at work; performance of daily tasks of life; mental functioning; and, sexuality. After this the list is reviewed and negative statements are replaced with more objective and accurate terms. The list is then broadened and used as the basis for the patient to write a composition about themselves.

Session 5:

The focus of this session was the detailed discussion of the diary and promotion of alternative explanations to the negative automatic thoughts in the diary. The self-esteem exercise was also completed. Both of these exercises had a clear and strong effect upon Mr G. Whilst carrying out the exercises he was able to identify the types of thinking errors he was making in social situations. With the self-esteem exercise, Mr G quickly identified how his derogatory self references in terms of the eight dimensions had contributed to and reinforced the dysfunctional assumptions about himself as shown on the DAS.

Session 6:

This session was designated as a review session, and the following changes in Mr G were identified.

Mr G described a considerable decrease in the frequency of avoidance of appointments at work. He was now attending all appointments made on his behalf and was more inclined to make appointments himself thus indicating an increase in his motivation. Mr G referred to himself as being more realistic in his interpretation of social situations. He was by this stage reporting being able to make alternative explanations of events *in vivo* no longer needing to use the diary after the event. Whilst his superior was away during the previous week Mr G was able to take on a more managerial role at work, something he reported previously avoiding.

Mr G's engagement in social activities had dramatically changed. He had recommenced playing football, hill walking and meeting his friends on a regular, twice weekly, basis. Mr G had not experience any somatic symptoms in the past three weeks. More peripheral changes he noted included: being more organised and active at home, less brooding, no further use of anxiolytic medication.

Mr G had become much more relaxed during therapy sessions as treatment progressed. Overt manifestations of anxiety were no longer apparent. Self-references and the conversation style used by Mr G had become more adaptive. For example he was more

inclined to use terms such as 'maybe' and 'perhaps'.

Self-Report Assessment Measures of Change.

		Session 1	Session 6
HAD	Anxiety	15	9
	Depression	6	5
BDI		19	6
Classification		Mild	Not depressed
DAS	Approval	-5	+4
	Love	-8	0
	Achievement	-1	+5
	Perfectionism	+3	+3
	Entitlement	-1	+1
	Omnipotence	+3	+7
	Autonomy	0	+2

These results are probably the most indicative of Mr G's progress. They show that along with his self-report of a change in his views and interpretations of situations, he can be seen to have made changes in his fundamental belief system, (most notably in the clusters of approval and love). These views were now more adaptive and could be deemed to have a direct effect on Mr G's day-to-day functioning.

DISCUSSION

A case of social phobia has been presented here. The therapeutic intervention was different from the norm with the patient being left largely responsible for setting his own behavioural exposure goals. The focus of treatment in this case was placed upon the dysfunctional thoughts and assumptions that the patient had both about the situations he was in and of himself.

Further to this (and the focus of this paper) is the more central examination of self-esteem. As a result of his work, the patient was able to identify his poor self-esteem and work towards changing it. Possibly as a consequence Mr G became more confident at entering social situations, and did so with a more positive outlook. It is suggested, therefore, that this focus on self-esteem has enabled the patient to improve his self-image and as a result can enter social situations not only with a more realistic evaluation of the situation but also of himself in these situations.

It is acknowledged that there are a number of flaws in this case report. These being that no formal self-esteem measures were taken. The approach has not been formally compared with any other treatment approach and the interpretations and importance of this approach has been made in a rather *ad-hoc* manner. None the less, it is argued that this case report hints at the impact that a more central focus on self-esteem can have on the individual's personal and general outlook. It is suggested, therefore, that further investigation needs to be made of self-esteem as a focus of treatment, rather than as McKay and Fanning (1992) suggest, as an incidental consequence of treatment.

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**THE COGNITIVE-BEHAVIOURAL MANAGEMENT OF PRADER-
WILLI SYNDROME: A CASE REPORT**

Abbreviated title: Treatment of PWS

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SUMMARY

Prader-Willi syndrome (PWS) has up until recently been treated using strict dietary control. Recent research, however, suggests that those individuals who have a lesser degree of intellectual impairment show food preferences and these can be used as judicious reinforcers. This report describes the case of a 23 year old woman with PWS and a poor behavioural history. The research findings were used to devise an effective management approach for this woman in an adult training centre setting.

INTRODUCTION

Prader-Willi Syndrome (PWS) went largely unrecognised until 1956 when it was described as a full clinical phenotype by Prader, Labhart and Willi. The classic features include: weak muscle tone and floppiness at birth; incomplete sexual development; varying degrees of intellectual impairment; and, poor social and emotional development. Most notable in this disorder is obesity. For a formal diagnosis to be made this characteristic obesity needs to emerge at approximately 1-3 years of age and be resistant to change (Holm, 1981).

Obesity in PWS is considered to be 'intractable and unamenable to dietary therapy' (Caldwell and Taylor, 1983). The characteristic voracious appetite will continue as long as food is available and is associated with considerable behavioural problems such as temper tantrums, stealing and eating unacceptable items such as food from rubbish bins, frozen food and animal foods (Holm and Pipes, 1976; Coplin, Hine and Gormican, 1976; Clarren and Smith, 1977). Pipes and Holm, 1973 suggested that individuals with PWS are never sated, have no food preferences, and are always hungry. In relation to the management of this disorder strict dietary control has until recently been the only treatment available along with appetite suppressants. The focus of such treatment has been to provide the greatest volume of food with low calorific value (Caldwell and Taylor, 1983).

Two findings have led to the advancement of treatment for individuals with PWS. Firstly Holm (1981) suggested that IQ in this population can extend beyond the 'retarded' range. Secondly a series of papers (cited below) suggest the possibility of the use of psychological techniques in the management of this condition. The findings suggest that firstly, contrary to previous beliefs, individuals with PWS do show definite food preferences and that it is related to a cognitive level of functioning, with those regarded as 'more able' being better able to show preferences than those regarded as 'less able', (mean IQ of 62.8 equals 'less able', and mean IQ of 77.7 equals 'more able' (Caldwell and Taylor, 1983). Secondly, Taylor and Caldwell (1985) found that more able individuals

with PWS prefer sweet foods and they would choose low volume, high preference foods over high volume low preference foods. Finally, in 1986 Caldwell, Taylor and Bloom used their prior knowledge of food preferences in PWS individuals to show that food could be used judiciously as a reinforcer for those with better cognitive skills.

In the case described below it was concluded that these ideas could be adapted into the form of a cognitive-behavioural management plan for the patient using food preferences to modify and reinforce behaviour.

CASE REPORT

Ms G is a 23 year old woman with PWS. In the referral she was described as 'unable to control her eating when outwith the family home and the supervision of her sister. Placements have failed in the past due to her problem'.

Ms G was born three months premature, and a diagnosis of PWS was given at twelve years of age. Ms G is the youngest of eleven children, her parents are both deceased, and she was now living with one of her sisters. Education was in ordinary school at primary level and at special school at secondary level once PWS had been diagnosed. Since 1989 she has been at two adult training centres (ATC), one for a period of ten months, after which she was expelled due to increasingly unmanageable behavioural difficulties. The second, a residential centre, was attended for three months and Ms G was again expelled due to extreme behavioural difficulties including: violence towards herself, other clients and property; stealing; and, running away. On expulsion the following was written in her report '...She would act in a very childish and demanding manner and when not getting her own way this would lead up to a temper which would either involve furious screaming or hitting out at and striking both students or co-workers, and on one occasion a visitor. She has a basic immaturity which would take a lot of overcoming, and while she is so immature there must be a fundamental doubt as to whether she can cope with a community life where part

of the philosophy is sharing'. With this history the tentative offer of a further placement had been made at a local ATC for a trial period of three days a week for three months. This was accompanied with a referral to clinical psychology for assistance.

The following features were noted in Ms G's community care assessment: 'She has some visual problems, simple language to an everyday level, and mobility limits due to her weight'. Further and more detailed information was collected from Ms G's sister. She reported that Ms G has a heightened interest in food which her parents did not curb or control in any way, the result being the emergence of temper tantrums when her sister took over her care and undertook a more restrictive approach. Other behavioural difficulties which have emerged include: lying; stealing of food or money; accusations made of staff stealing; and one occasion of abuse. Manipulation of workers by playing one person off against another to gain food or preferential treatment was also reported by Ms G's sister.

TREATMENT PROGRAMME

Intellectual testing, using the Wechsler Adult Intelligence Scale-Revised (Wechsler, 1981) (WAIS-R), was carried out with Ms G to determine her level of cognitive functioning to consider the appropriate use of the methods described by Caldwell *et al* (1986). Results showed Ms G to have a full scale IQ of 57, verbal IQ of 62 and a performance IQ of 55. This puts her in the range of 'mild' learning difficulties and in Caldwell and Taylor's (1983) 'less able' group. On the WAIS-R verbal subtest of comprehension, however, Ms G showed a noticeably good performance which reflected her general level of comprehension.

On this basis it was decided to employ the principles suggested by Caldwell *et al* (1986) with this client. This would be combined with cognitive techniques to encourage a more altruistic outlook in Ms G. Also her sister and keyworker

would be closely involved to maintain a consistent approach to management.

In preparation for Ms G's entrance into the ATC a talk was given to the staff on both the condition and features of PWS, and the specific characteristics of Ms G. Staff were advised on how to recognise these characteristics, and how to deal with any problematic behaviours which would arise. The following points were made in relation to Ms G and include observations and techniques which Ms G's sister has found to be effective in the management of her sisters behaviour. This also constituted the global management plan for staff at the ATC with the advice that *consistency* is the best approach in the management of Ms G and PWS at the centre. Specific guidelines were given to all members of staff about what food and drinks Ms G was allowed and when.

Ms G responds best to a firm almost authoritarian approach, i.e. knowing the rules. She tends to capitalise on manipulating those people who are friendly and giving towards her by repeatedly asking questions she knows the answers to, in an attempt to change the answer or action in her favour. Staff were therefore advised to answer questions only twice and not to give in to her out of sympathy and not to be cornered into a discussion in which she may try to alter rules. Ms G can be reasoned with but she is very skilled at negotiating and can use discussion as a medium for manipulation and this it was advised should best be avoided by staff.

It was stressed that Ms G's key and co-worker would be the only ones who could make decisions regarding Ms G and if changes were requested then they would need to be consulted. This would therefore prevent Ms G manipulating staff. Quiet or brooding behaviour tended to indicate Ms G planning ways of getting food or changing rules, and therefore staff were advised to look out for this then distract Ms G and to generally keep her busy, i.e. using the principles of gentle teaching (McGee, Menolascino, Hobbs and Menaisek, 1987). In reprimanding her, staff were advised to be clear to Ms G as to why she was being reprimanded, and that her key

worker will be informed. She should then be distracted thereby not allowing her to brood, argue back, or begin a temper tantrum and praised her for her ability to continue after the reprimand. This is again following the principles of gentle teaching (McGee *et al*, 1987).

Methods which should absolutely not be used by staff included discussing Ms G's diet with her. Giving or promising her food as a way of either pacifying her, changing or maintaining her behaviour. Ms G's behaviour, if good, will only be rewarded at home by Ms G's sister and not by staff at the ATC.

Arrangements were made for a diary to be sent back and forth between Ms G's sister and the key worker with reports of Ms G's behaviour. Good behaviour would be rewarded with preferred foods for supper only at home by Ms G's sister, therefore following the principles of Caldwell *et al*'s approach (1986). Inappropriate behaviour, i.e. temper tantrums, arguing and not conforming to the rules of the ATC, would result in Ms G being sent home immediately.

Discussion followed this to determine the staff's attitude towards this hard-line approach. The medical and psychological health of Ms G as well as the research were offered as the main premises for this strict approach.

Following this meeting a further meeting was arranged with Ms G, her sister, her key worker, the head of the ATC and the therapist, to explain the management plan to Ms G. Her work program at the ATC was planned and explained with an emphasis on making the day as easy as possible. In this way Ms G would not be put into challenging situations e.g. a cookery programme. Mealtimes were explained for everyone so that the format was clearly understood by all. It was made clear to Ms G that her key worker would be in charge of her, and that any requests or questions should be directed towards her. Finally the system of rewards and punishment was explained to Ms G with emphasis being placed on the rewards available for appropriate behaviours.

Ms G began at the ATC the following week and regular contact was maintained to monitor her progress, this involved: unscheduled visits to the ATC to meet with Ms G and discuss her progress; and, scheduled weekly visits with Ms G's key worker at the ATC and with Ms G and her sister at home to corroborate information on Ms G's behaviour and progress. These visits were also used to encourage more responsible behaviour in Ms G and to reinforce appropriate behaviours at the ATC through discussion with Ms G and her sister. Although no formal measures had been taken, knowledge of Ms G's behaviour on previous placements, clinical observation and Ms G's sister's and key worker's reports of her behaviour on this placement were used as a guide to her progress.

After three weeks Ms G displayed one behavioural outburst at the centre. This was relating to food and her trying to change what she was to have for lunch. Unfortunately Ms G's key worker was not present and an inexperienced member of staff was unable to contain the situation effectively. Ms G was sent home immediately. No further outbursts occurred over the three months. It was felt that Ms G was testing out the management plan with this outburst. The policy of checking out Ms G's behaviour by the therapist, Ms G, her sister, and keyworker led to a noticeable decrease in the amount of inaccurate information Ms G was giving.

During the three month period Ms G began to display more responsible and adult-like behaviours such as using her own money to replace her glasses which she had previously repeatedly broken during temper tantrums, and offering to donate her toys and dolls to a local children's hospital. Generally a more generous use of money was noted. Ms G's conversation became less boisterous and attention-seeking, and revolved less around herself.

A meeting was held at the ATC at the end of the three month trial. The following comments and recommendations were made: Ms G had 'proved confident and competent' in a number of her programs, most notably social skills. She had begun taking part in trips outside of the ATC to the library and

the shops which had proven to be a successful endeavour. Ms G 'had behaved in a very reasonable and acceptable manner'.

Overall the placement was felt to be successful, but it was felt that part of that success was attributable to Ms G having the knowledge that she was on a trial period at the centre. It was therefore agreed that her attendance at the centre could be maintained under the same premises as before. When Ms G was reviewed after six months she was still attending the ATC on a three days per week basis. Her behaviour was still appropriate, and no further outbursts had occurred. An increase in the number of days attended each week was currently being considered.

DISCUSSION

Since its formal recognition in the 1950's the focus of treatment for PWS seems to have been the strict control of diet, the assumption being that a low IQ restricts any treatment plans which require the cooperation of the patient. Since the 1950's, however, there has been a broad development in the field of learning difficulties including better methods of assessment, teaching, individual programme planning and management of behavioural difficulties.

This case has been presented as an example of the therapeutic application of the research findings of Caldwell *et al* (1986) relating to food preferences in individuals with PWS. They have suggested that food preferences could be used judiciously as a reinforcer. In the case presented it was shown that food could be used as a method of modifying and rewarding behaviour in a patient who was competent enough to understand the programme being used with her. The result was that behaviour was more appropriate in situations which had previously been problematic for her. Combined with this was the use of the principles of other techniques such as 'gentle teaching' and positive reinforcement. The result, therefore, was a multimodal approach carefully tailored to the needs, abilities and preferences of both the client and the carers. In this way the behaviour has been

successfully managed, staff and family have been effectively involved, and a desired change has been observed in the client's behaviour from which all involved have benefitted. The success of this complex approach with this client was probably a result of the committed involvement and consistency of family and ATC staff. It is suggested, therefore, that if the client has the ability, and family and staff are committed to the approach, this format of treatment may be used in other cases of this nature.

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**THE EFFECT OF CHILDHOOD MEMORIES ON THE DEVELOPMENT
OF A PHOBIA: A CASE REPORT**

Abbreviated title: Childhood memories and phobia

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SUMMARY

Although early experiences are important in the development of phobias and are recognised as such, it is rare that focus is given to the initial incident within treatment. Reported here is the case of a 29 year old woman with a vomit phobia. The phobia developed as a result of traumatic childhood experiences in hospital. Treatment focused upon the childhood experiences and restructuring cognitive errors relating to this experience.

INTRODUCTION

Phobias have generally been thought develop through direct or vicarious reinforcement (Rachman, 1977). The fear usually builds up through repeated, frightening experiences. Simple phobias are confined to a single fear, such as of spiders or heights. A graded exposure to the feared object is generally considered the most effective in the treatment of simple phobias (Emmelkamp, 1982). Last (1984) has also supported the use of cognitive therapy to accompany behavioural techniques. The function of these two approaches is to aid and increase exposure between appointments, and to aid discussion of completed exposure exercises. Applied relaxation, and controlled breathing techniques can also be utilised as an aid to controlling the somatic aspects of the problem (Ost, 1987).

Butler (1989) argues that although common in childhood, fears often disappear by age 6 and that simple phobias often develop out of childhood fears. She suggests that it is certainly not necessary to know the exact cause of a phobia to treat it successfully. With respect to the development of fears Herbert (1991) suggests that infants and very young children fear things in their immediate environment such as being left alone, strangers and separation. Preschool children show fear to a wider range of stimuli such as ghosts, monsters and the dark. Older children show fears of a more realistic nature and include; physical injury, health and school related issues. Separation, the unknown and punishment, appear to be the main theme of fears of the young child.

The issue of separation in childhood has been extensively reviewed and researched by Bowlby (1973). His own theory includes both cognitive and evolutionary aspects of development. Bowlby argues that fear is most likely to occur when a child is separated from the attachment figure. The core of the theory suggests that it is secure attachments which are the basis of growth and the resulting development of emotional stability. Most children, he argues, after the age of three years become increasingly able to cope in a strange place but this is conditional upon the following: the presence of a familiar subordinate

attachment figure; the child being healthy, and not alarmed; and, the child being aware of where the mother is and confident in her return at short notice. Bowlby (1973) has also explored the importance of inanimate objects to young children. He highlights their 'tremendous importance for a child's peace of mind'. For example he describes the case of a young child requesting his 'squirrel' on coming round from an anaesthetic following a tonsillectomy. Once he had this toy he went to sleep peacefully.

Newson and Newson (1968) have provided a good deal of the research exploring the effects of brief stays in hospital on young children. In terms of how this may effect the development of specific fears and phobias they argue that exhibition of unusually intense fears of a particular situation can often be traced back to a specific experience connected with that situation. Experiences relating to hospitals is one of the examples they often cite.

Brown and Harris (1978) look at the importance of the loss of the attachment figure in early life and its effect on future emotional development. They argue that loss of the attachment figure at an early age can increase the vulnerability of the child to problems relating to emotional development.

So in summary, phobias can develop from childhood fears. Separation from and the loss of the attachment figure can both amplify a fear, and lead to long term emotional problems. Finally, the experience of brief stays in hospital can lead to separation anxiety and depending upon the experience, long term emotional difficulties. 'The only conditions at present known that reduce appreciably the effects of separation from the attachment figure are familiar possessions... strange people, strange places and strange proceedings are always alarming; and they are especially alarming when encountered alone' (Bowlby, 1973).

CASE REPORT

Mrs D, aged 29 years, was referred with a fear of both hospitals and anaesthetics.

She was due to have an operation to remove her wisdom teeth and was referred because of her difficulty in attending hospital appointments. Mrs D described that for as long as she could remember she had a fear of being sick and seeing other people being sick. This fear was affecting her to such an extent that she felt it was controlling her life. She constantly thought that people were going to be sick in public. She had become hypervigilant and was monitoring people's behaviour. If they looked as if they may be sick e.g. bending down, yawning, looking 'off colour' she would get off the bus, cross the road or leave the room. Mrs D was also unable to walk down a street in a straight line as she would be worrying that people may be being sick in doorways and so she would skirt around doorways and alleyways. Thoughts that would accompany her somatic feelings of anxiety in these situations such as heart racing, shaking and shortness of breath included: 'what will I do?', 'how can I get out of this situation as quick as possible?'. There did not appear to be any specific fear such as someone being sick on her, or that someone may choke whilst being sick and she would have to give the kiss of life.

Mrs D had last been sick herself ten years previously, and she recalled this as having been very distressing to the extent that she needed comforting by her father and spent the night in his bed. The situations she was currently avoiding included; public and work toilets, public transport on Fridays (the reasoning being that because it is the end of the week people would go for a drink and she was therefore at more risk of seeing someone being sick), socialising, and using lifts. There had been no previous psychiatric history, no current medication, and no evidence of depression. In the first assessment session she was unable to identify any clear origin to this or a time when it had first become apparent.

As the case stood, the maintaining factors and the phobia itself, seemed clear. What was unclear however was the origin of the fear. At her second appointment Mrs D reported that there had been events in her childhood that she felt may be relevant to her current fears, but she was unsure as to their importance. Mrs D described the following events:

At roughly age three, she recalls being sick at night in her cot and her mother not immediately attending to her so that she became distressed but could not call out to her, this resulted in her banging on the wall to try and summon her mother. At age 5 she was taken to hospital to have her tonsils out. She recalls being left at the hospital by her parents, and feeling frightened of the ward sister who reprimanded her on a couple of occasions during her stay. When she came round from the anaesthetic she recalls being alone, lying on her stomach, feeling frightened and not being able to turn her head to see her bracelet, which she reported as something which provided her with security as a child. This again distressed her and she has subsequently been confused as to why these memories have remained so vivid.

Shortly after coming round from the anaesthetic Mrs D recalls that she was sick '27 times'. She distinctly recalls the number of times, and remembers counting. She was again reprimanded by the ward sister who, on a couple of occasions, would change the bedclothes and Mrs D was sick again. Throughout this her mother was not present and Mrs D recalls being distressed at being alone, and at not being comforted whilst she was sick and being told off. On the occasions her mother did visit her in hospital she was very attentive to another girl on the ward who apparently came from a 'problem family'. Mrs D's mother felt that she needed attention, and so brought both children gifts, she also encouraged her daughter to befriend and look after the other girl. Mrs D interpreted this at the time to mean that her mother no longer loved her. The year after Mrs D had been in hospital her mother became terminally ill and spent the next two years in hospital before she died when Mrs D was aged eight.

The formulation made at this point was that Mrs D's phobia seemed to have developed in her early childhood as a result of the events she described above. On both of the occasions she had been ill, at ages 3 and 5, her mother's presence and comfort was paramount, but was not immediately available or not, as she felt, wholly given in the case of the incident in the hospital. Mrs D had very clear memories of the events especially of her time in hospital. She was unclear

as to why these events had remained so vivid in her mind. From what Bowlby (1973) suggests the combination of being away from her mother, in a strange place and being scolded and being ill was a 'lethal combination', and it is not surprising that intense fear and phobic associations developed. At assessment Mrs D completed the The Hospital Anxiety and Depression Scale (HAD) (Zigmond and Snaith, 1983). This was used as a general screening device to gain an indication of the level of caseness of Mrs D's difficulties. Her anxiety score equalled 14, indicative of caseness, and her depression score equalled 2.

TREATMENT PROGRAMME

It was considered important in this case that the origins of the phobia be explored in detail so that Mrs D could have a better understanding of her fear, her current responses, and the creation of threatening situations.

Session 1:

This was spent discussing Mrs D's childhood, with a focus on her stay in hospital and the time before her mothers death. From discussion it could be gleaned that because of her experience in hospital Mrs D had developed very fixed, and somewhat distorted ideas about being sick. Her memories of being sick were rather childlike. She had not put any adult meaning or interpretation upon the events, e.g. 'when I was sick there was piles of it and it seemed to be pouring out of my nose and mouth and it wouldn't stop coming'. The session was spent going through each memory and restructuring them into adult interpretations. As this was done the following changes were made: The ward sister was trying to be friendly with her sarcastic scolding and the more genuine reprimands from the nurse when she was being repeatedly sick had more meaning to an adult. She was not surprised as an adult that she was reprimanded for this and indeed was impressed by the ward sister's overall level of patience with her.

Her recovery from the anaesthetic and searching for her bracelet was explored.

Mrs D described a deep attachment as a child to this bracelet. When it was not there after the operation (probably removed, as is standard procedure) Mrs D felt very distressed, no-one was present and her familiar comforter had been removed. A link between this separation anxiety and being sick seemed to have been established, and it was suggested to Mrs D that she had made an association between being sick being separated from her attachment figure and object of comfort.

Her mother's visiting again changed perspective under adult scrutiny. Mrs D was able to see that her mother was concerned about the other girl who, Mrs D does not recall having any of her own visitors. As an adult she was more appreciative of her mother's behaviour and quickly had a more balanced view of the events. Again her mother not being present at the hospital when she was ill could be accounted for by old hospital visiting hours policies and was not because her mother did not care.

It was suggested to her that an association had been built up from her childhood memories and interpretations. With a more adult perspective she would be able to reinterpret events around her now. Homework set from this session was for Mrs D to spend half an hour sometime during the week watching people in the town and checking out her assumption that they are going to be sick rather than immediately escaping from the situation.

Session 2:

In this session homework was reviewed and Mrs D reported carrying out the task successfully. Also during this week she had an appointment at the hospital regarding the removal of her wisdom teeth. She described this event as 'a nightmare' and reported having flashbacks to the visit afterwards and was still 'worried and depressed' about her ability to cope with the event. When describing the event it was apparent that she was focusing heavily on the negative anxious thoughts which could be related back to her childhood fears: that there would be sick everywhere, and that she felt very alone and

unsupported. This provided a good opportunity to show how the associations of her childhood memories and the experience of being sick were being linked.

Through discussion Mrs D identified her thinking errors and was also able to pick out some of the positive aspects of her visit to the hospital, e.g. she had attended and not defaulted the appointment and she went on her own. Her ideas about the physical presence of vomit were also looked at, i.e. that people do not vomit endlessly and from the nose and mouth. Homework set for this session included further observations of people in the street and for Mrs D to try and walk in straight lines in the street rather than skirting doorways and alleyways.

Session 3:

Mr D attended this appointment feeling very accomplished and pleased with herself. She was able to spend much more time watching people in public places without escaping. She made more realistic interpretations of events and was also now walking in straight lines and not checking round corners and into alleyways. Over the previous week she reported having sat down and thought through her experiences as a child more comprehensively, and seeing how the child thoughts had permeated through to adulthood but that when examined they were not adult, rational thoughts.

Although Mrs D was upset at her mother's death she feels that she grieved appropriately and that the support she had from her mother was replaced by the support of her father and now by her husband. The importance of the loss of her mother at that time, and the subsequent effect this may have had on her experience of this problem was also discussed. Mrs D felt that she had progressed quite significantly over the previous week and was keen to progress quickly now. The focus of treatment therefore turned towards a graded exposure of feared events and situations.

Sessions 4 and 5:

Mrs D had begun to keep a diary, of her own accord, in which she would record

her exposure and reinterpretation of events. Over the week she had begun to use the toilet at work again, was trying not to rush past people in the street, and sat next to a man on the bus journey home from work (approximately a 40 minute journey) whom she could smell had been drinking. She was watching television looking for opportunities to see people being sick also. Mrs D was next required to spend some time at the local hospital. Mrs D spent two periods of 45 minutes each walking around the grounds of a hospital looking into windows and challenging her negative thoughts. Mrs M had been given an appointment for the removal of her wisdom teeth and was now interpreting this event as a challenge rather than as something to be dreaded. She was also able to distinguish between the anxiety of seeing someone being sick whilst in hospital and the natural anxiety experienced before entering hospital.

Sessions 6 and 7:

There had been a number of incidents of vomiting on the television over the previous week and Mrs D had watched all of these and was advised to video some to provide opportunity for repeated exposure. She now reported avoiding situations, such as dark alleyways, because of more realistic concerns. Realistic scenarios of people being sick and Mrs D's role in the situation were discussed as preparation for a time when she does experience someone being sick first hand. She was also given a tape of vomit sounds to listen to. Although she found this very anxiety provoking she was able to listen. It was felt appropriate by both the therapist and the patient to terminate treatment here with one follow up appointment after her discharge from hospital.

Following her stay in hospital, with which she coped well, Mrs D was discharged at this time her anxiety score on the HAD was 8 and depression score was 1.

DISCUSSION

In the treatment of phobias the usual approach is to address the avoidance and anxiety symptoms using a hierarchy of graded exposure to the feared stimulus.

Little attention is paid to the cause or original incident leading to the phobia. Beck's (1976) cognitive model suggests that early experiences lead to the formation of assumptions or schemata about the world and oneself. These are then used to make an evaluation, interpretation and understanding of subsequent events. This, Beck argues, can lead to either normal or abnormal functioning depending upon the nature of these early experiences. Although this is the model developed in relation to depression it has been widely used for the interpretation of other disorders including phobias. There are few cases presented in the literature which serve as examples of this model. The main focus tends to be upon treatment of and not the development of the problem.

Presented here is a case of a vomit phobia in which the initial experiences of vomiting had, it appeared, lead to the development of dysfunctional schemata. In this case it was felt that the patient's assumptions and interpretation of events had remained those of a young child, and as a result were distorting her interpretation of events now as an adult.

In the treatment of this patient the importance of attachment, separation and inanimate objects (Bowlby, 1973), the effects of hospitalisation on a young child (Newson and Newson, 1968), the effect of the loss of the attachment figure (Brown and Harris, 1978) and Beck's (1976) cognitive model were used to explain the patient's early and subsequent experiences. Once this had been understood and the critical events occurring as a child and subsequent experiences been reinterpreted, the patient was able to enter a programme of graded exposure with a greater understanding of her anxiety and its accompanying negative evaluation of events and circumstances.

It is concluded, therefore, that contrary to the popular model in some cases determining the cause and reinterpreting this as an initial stage in therapy *can* be of great importance.

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RESEARCH PORTFOLIO APPENDIX

Section 1: Major Research Project Literature Review

Section 2: Major Research Project Proposal

Section 3: Major Research Project Paper

Section 4: Small Scale Service Evaluation Project

Section 5: Single Clinical Case Research Studies

SECTION 1: MAJOR RESEARCH PROJECT LITERATURE REVIEW

Appendix 1: Notes for authors - 'Mortality'

MORTALITY

Notes for Contributors

Mortality welcomes original contributions from all parts of the world on the understanding that their contents have not previously been published nor submitted elsewhere for publication. All submissions will be sent anonymously to independent referees. It is a condition of acceptance that papers become the copyright of the publisher.

Manuscripts

Manuscripts may be in the form of: (1) research papers (not exceeding 8,000 words); (2) reviews; (3) short reports for rapid publication (not exceeding 2,000 words); or (4) letters to the Editors. Four complete copies should be submitted to the Editors, *Mortality*, School of Cultural and Community Studies, Arts B, University of Sussex, Falmer, Brighton BN1 9QN, United Kingdom.

All submissions should be in the Harvard style (American Psychological Association, *Publication Manual*. Fourth edition, 1994). Papers should be typed on one side of the paper, double spaced (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

The first page should include the title of the paper, name(s) of the author(s), and for each author a short institutional address and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including fax number and e-mail address if possible) of the author to whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain an **abstract** of not more than 200 words. The third page should repeat the title as a heading to the main body of the text. Within the text section headings and subheadings should be typed on a separate line without numbering, indentation or bold or italic typeface.

References

References should be in the Harvard style. All publications cited in the text should be listed following the text; similarly, all references listed must be mentioned in the text. Within the text, references should be indicated by the author's name and year of publication in parentheses, e.g. (Sloane, 1991) or (Howarth & Jupp, 1995), or, if there are more than two authors, (Boddington *et al.*, 1987). Where several references are quoted consecutively within the text, the order should be chronological, e.g. (Sloane, 1991; Dickenson & Johnson, 1993), or within a single year, alphabetical (Dinnage, 1990; Kellehear, 1990; Williams, 1990). If more than one paper from the same author(s) and year are listed, the date should be followed by (a), (b), etc., e.g. (Walter, 1991a).

References should be listed alphabetically by author on a separate sheet(s) (double spaced) in the following standard form, capitalisation and punctuation:

- a) for periodical articles (titles of journals should *not* be abbreviated):
Kselman, T. (1988) Funeral conflicts in nineteenth-century France, *Comparative Studies in Society and History*, 30, 312-332.
- b) for books:
Parry, J. P. (1994) *Death in Banaras* (Cambridge, Cambridge University Press).
- c) for chapters within multi-authored books:
Young, Sir G. (1981) Hospice and health care, in: C. Saunders, D. H. Summers & N. Teller (Eds), *Hospice: The Living Idea* (London, Edward Arnold).

Illustrations

All illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Fig. 3). Each should be submitted on a separate sheet of paper, numbered on the back with Figure number (Arabic numerals) and the title of the paper. The captions of all figures should be submitted on a separate sheet, should include keys to symbols and should make interpretation possible without reference to the text.

Figures should ideally be professionally drawn and designed with the format of the journal (175 x 248 mm) in mind and should be capable of reduction.

Tables

Tables should be submitted on separate sheets, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

Proofs

Proofs will be sent by air mail to the author nominated for correspondence. Proofs are supplied for checking and making essential typographical corrections, not for general revision or alteration. Proofs must be returned (by air mail or fax) within 72 hours of receipt.

Offprints

Fifty offprints of each paper are supplied free to the nominated author for correspondence for further distribution, together with a complete copy of the relevant issue of the journal. Additional offprints may be purchased and should be ordered when proofs are returned. Offprints are sent approximately two weeks after publication.



CARFAX

SECTION 2: MAJOR PROJECT RESEARCH PROPOSAL

Appendix 1: Notes for authors - The D.Clin.Psy. course handbook description of
The Chief Scientists Office mini-project grant application
guidelines

Appendix 2: Letter to subjects

Appendix 3: Consent form

Appendix 4: Project Questionnaire

2. Major Research Project Proposal

The Research Proposal should be laid out according to the format described below. This format is based upon the application for a mini-project grant in Health Services Research (SOHHD - Chief Scientist Office). Trainees may find that forms provided by ethical committees are substantially similar to this and this may be an acceptable alternative format.

- 2.1 Applicants - names and addresses including the names of co-workers and supervisor(s) if known.
- 2.2 Title - no more than 15 words.
- 2.3 Summary - No more than 300 words, including a reference to where the study will be carried out.
- 2.4 Introduction - of less than 600 words justifying the relevance to the Health Service and summarising previous work in the field drawing attention to gaps in present knowledge.
- 2.5 Aims and hypothesis to be tested - these should wherever possible be stated as a list of questions to which answers will be sought.
- 2.6 Plan of investigation - consisting of a statement of the practical details of how it is proposed to obtain answers to the questions posed. The proposal should contain information on Research Methods and Design i.e.
 - 2.6.1 Subjects - a brief statement of inclusion and exclusion criteria and anticipated number of participants.
 - 2.6.2 Measures - a brief explanation of interviews/observations/rating scales etc., to be employed including references where appropriate.
 - 2.6.3 Design and Procedure - a brief explanation of the overall experimental design with reference to comparisons to be made, control populations, timing of measurements etc. A summary chart may be helpful to explain the research process.
 - 2.6.4 Settings and equipment - a statement on the location(s) to be used and resources or equipment which will be employed (if any).
 - 2.6.5 Data analysis - a brief explanation of how data will be collated, stored and analysed.
- 2.7 Purpose - this should state the underlying purpose of the project. The applicants should indicate to what use the research findings may be put.
- 2.8 Timescales - the proposed starting date and duration of the project.
- 2.9 Ethical approval - stating whether this is necessary and, if so whether it has been obtained.

APPENDIX 2

Anna M Wroblewska,
Department of Psychological Medicine,
Mental Health Unit,
Gartnavel Royal Hospital,
Glasgow.

Dear Sir,

I am carrying out a study on Funeral Directors as a part my post graduate training in Clinical Psychology at the University of Glasgow. Mr may have spoken to you already about this. This letter is to provide you with some more information about the study.

Background

In research which has been carried out in the areas of occupational stress and psychological profiling, a variety of professions have been considered, covering both white and blue-collar workers.

Beyond this, research is now emerging on the development of psychological stress in different professionals who are exposed to a variety of 'risk factors' for disorders such as anxiety and post traumatic stress. To date in the populations who have been researched, encountering death has been identified as a risk factor of psychological problems for those who have some indirect or peripheral involvement with deathwork e.g. survivors, police and disaster workers.

It would appear that no research has been conducted on the population who deal directly with deathwork on a daily basis namely funeral directors. With the increase in the frequency of traumatic and untimely deaths occurring from e.g. disasters and road traffic accidents the role of the funeral director has changed to provide more grief counselling to families and survivors and to possibly be more skilled in embalming and reconstruction work.

It is of clinical importance to determine the psychological profile of this population, to consider what anxiety their work causes and how they cope with stress. The latter two aspects are of great importance in future clinical work with populations who have not developed such coping skills when working with the dying, dead or bereaved i.e the aforementioned police and disaster workers.

The aims of the study are:

- 1- To gain a psychological profile the funeral director, something which has not been done up till now.
- 2- To measure aspects relating to work which have been used before on American funeral directors to see how the two populations compare and consider reasons why they may be the same or different.
- 3- To measure specific issues of occupational stress and coping methods to further understand the coping strategies of this population with the aim of advising other people

who have to do disaster work but are not as well prepared on a personal level.

4- To compare those who are involved in disaster work with those who are not. Your involvement in the study simply requires you to complete and return the attached questionnaire.

The Questionnaire

Part 1-You and your background.

Part 2-General questions about your health and mood.

Part 3-Questions regarding your attitudes towards death.

Part 4-Questions about the way you cope with the difficult aspects of your work.

Confidentiality

All information collected by the study will be treated in a highly confidential manner i.e. no names or personal identifiers will be used, you will be given a code number. Information will not be passed on to other respondents, to other research projects in the University or to any other third party. Reports and publications will present results in a way that avoids the possibility of individuals being identified. I will provide full feedback of results to participants within the constraints of maintaining confidentiality.

In considering taking part in this research there are two important points I would wish you to be aware of.

1- This population has not been profiled before and this represents a significant gap in the research.

2- It is of clinical importance to determine what methods of coping are being used by individuals to further understanding, and aid the development of methods of treatment for those individuals who are not coping when dealing with issues of death.

Finally it should be understood that no aspect of this study is designed to be voyeuristic or provide an exposé of individual funeral directors or the profession as a whole. The main aim of the study is to broaden the understanding of occupational stress and coping styles. If you want more information or just to discuss the project please contact me at the following address:

Thank you for your time and help.

Anna M Wroblewska B.Sc.(Hons), M.Sc.

APPENDIX 3

STUDY OF FUNERAL DIRECTORS

Department of Psychological Medicine, Mental Health Unit, Gartnavel Royal Hospital, Glasgow.

CONSENT FORM

I agree to providing my name and address
and being approached by the research study
being done by Anna Wroblewska

I do not want to take part in the study
being done by Anna Wroblewska

Signed:

Name:

Contact Address:

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PRIVATE AND CONFIDENTIAL

STUDY OF FUNERAL DIRECTORS

QUESTIONNAIRE

Thank you for agreeing to take part in this study. The questionnaires included ask you a variety of questions about you your health and how you cope with your work. Please answer each question in each of the questionnaires and do not leave any out. Please then return the questionnaire in the stamped addressed envelope provided

The questionnaire has several parts:

- 1 Questions about you and your background**
- 2 General questions about your health and mood**
- 3 Questions regarding your attitudes towards death**
- 4 Questions about the way you cope with the difficult aspects of your work**

I would like to stress that the answers given in this questionnaire will be treated in the strictest confidence and will not be passed on to anyone else.

Many thanks for your help!

Anna M Wroblewska

Dept of Psychological Medicine,
Mental Health Unit
Gartnavel Royal Hospital
Glasgow

1. BACKGROUND INFORMATION

1. Your age. _____

--	--

2. Your marital status _____

--	--

3. Do you have any children? YES _____ NO _____

--	--

4. Number of years as a funeral director. _____

--	--

5. Please describe your training _____

--	--

6. Do you routinely perform embalming and bodywork? YES _____ NO _____

--	--

7. Has your training involved bereavement counselling? YES _____ NO _____

--	--

8. In the last year how many cases of the following have you dealt with, approximately.

Natural deaths _____

--	--

Accidental Deaths _____

--	--

Suicides _____

--	--

Murders _____

--	--

Childhood deaths _____

--	--

9. Have you been involved professionally in any major disaster work? YES _____ NO _____

--	--

If yes please state where _____

--	--

10. Are any other members of your family in the funeral directing profession?

YES _____ NO _____

--	--

If yes how many _____

--	--

2. YOUR GENERAL HEALTH

Please read this carefully.

I would like to know if you have had any medical complaints and how your health has been in general, *over the past few weeks*. Please answer all the questions on the following pages simply by ringing the answer which you think most nearly applies to you. Remember that I want to know about present and recent complaints, not those that you have had in the past.

It is important that you answer all of the questions.

Have you recently

A1 - been feeling perfectly well and in good health.	better than usual	same as usual	worse than usual	much worse than usual
A2 - been feeling in good need of a tonic	not at all	no more than usual	rather more than usual	much more than usual
A3 - been feeling run down and out of sorts	not at all	no more than usual	rather more than usual	much more than usual
A4 - felt that you are ill	not at all	no more than usual	rather more than usual	much more than usual
A5 - been getting any pains in your head	not at all	no more than usual	rather more than usual	much more than usual
A6 - been getting a feeling of tightness or pressure in your head	not at all	no more than usual	rather more than usual	much more than usual
A7 - been having hot or cold spells	not at all	no more than usual	rather more than usual	much more than usual

B1 - lost much sleep over worry	not at all	no more than usual	rather more than usual	much more than usual
B2 - had difficulty in staying asleep once you are off	not at all	no more than usual	rather more than usual	much more than usual
B3 - felt constantly under strain	not at all	no more than usual	rather more than usual	much more than usual
B4 - been getting edgy and bad tempered	not at all	no more than usual	rather more than usual	much more than usual
B5 - been getting scared or panicky for no good reason	not at all	no more than usual	rather more than usual	much more than usual

B6- found everything getting on top of you	not at all	no more than usual	rather more than usual	much more than usual
B7 - been feeling nervous and strung up all the time	not at all	no more than usual	rather more than usual	much more than usual
C1 - been managing to keep yourself busy and occupied	more so than usual	same as than usual	rather less than usual	much less than usual
C2 - been taking longer over the things you do	quicker than usual	same as usual	longer than usual	much longer than usual
C3 - felt on the whole you were doing things well	better than usual	about the same	less well than usual	much less well
C4 - been satisfied with the way you've carried out your task	more satisfied	about same as usual	less satisfied than usual	much less satisfied
C5 - felt you are playing a useful part in things	more so than usual	same as usual	less useful than usual	much less useful
C6 - felt capable of making decisions	more so than usual	same as usual	less so than usual	much less capable
C7 - been able to enjoy your normal day to day activities	more so than usual	same as usual	less useful than usual	much less useful
D1 - been thinking of yourself as a worthless person	not at all	no more than usual	rather more than usual	much more than usual
D2 - felt than life is entirely hopeless	not at all	no more than usual	rather more than usual	much more than usual
D3 - felt that life isn't worth living	not at all	no more than usual	rather more than usual	much more than usual
D4 - thought of the possibility that you might make away with yourself	definitely not	I don't think so	has crossed my mind	definitely have
D5 - found at times you couldn't do anything because your nerves were too bad	not at all	no more than usual	rather more than usual	much more than usual
D6 - found you were wishing you were dead and away from it all	not at all	no more than usual	rather more than usual	much more than usual
D7 - found that the idea of taking your own life kept coming into your mind	definitely not	I don't think so	has crossed my mind	definitely have

A	
D	

Read each item in this questionnaire and place a tick in the box opposite the reply which comes closest to how you have been feeling in the last week. Your first reaction to an item is probably the most accurate than a long thought out response. Do not leave any out

I feel tense and wound up

- Most of the time
- A lot of the time
- Time to time , Occasionally
- Not at all

I have lost interest in my appearance

- Definately
- I don't take so much care as I should
- I may not take as much care
- I take just as much care as ever

I still enjoy the things I used to enjoy

- Definately as much
- Not quite so much
- Only a litte
- Hardly at all

I feel restless as if I have to be on the move

- Very much indeed
- Quite alot
- Not very much
- Not at all

I get sort of frightened as if something awful is about to happen

- Very definately and quite badly
- Yes but not too badly
- A little but it does not worry me
- Not at all

I look forward with enjoyment to things

- As much as I ever did
- Rather less than I used to
- Definately less than I used to
- Hardly at all

I can laugh and see the funny side of things

- As much as I always could
- Not quite so much now
- Definately not so much now
- Not at all

I get sudden feelings of panic

- Very often indeed
- Quite often
- Not very often
- Not at all

Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I can enjoy a good book or radio or TV programme

- Often
- Sometimes
- Not often
- Very seldom

I feel cheerful

- Not at all
- Not often
- Sometimes
- Most of the time

I feel as if I an slowed down

- Nearly all the time
- Very often
- Sometimes
- Not at all

I can sit at ease and feel relaxed

- Definately
- Usually
- Not often
- Not at all

I get sort of frightened feeling like 'butterflies' in the stomach

- Not at all
- Occasionally
- Quite often
- Very often

On this questionnaire are groups of statements. Please read each group of statements carefully. Then pick out in each group which best describes the way you have been feeling in the PAST WEEK, INCLUDING TODAY! circle the number beside the statement you picked. Be sure to read all the statements in each group before making your choice.

- 1 0 I don't feel much different from most other people my age
 1 I feel somewhat different from most other people my age
 2 I feel so different from most other people my age that I choose pretty carefully who I'll be with and when
 3 I feel so totally alien to most other people my age that I stay away from them at all costs
- 2 0 I care as much about the consequences of what I am doing as most other people
 1 I care less about the consequences of what I am doing than most other people
 2 I care much less about the consequences of what I am doing than most other people
 3 I often think 'Let the consequences be damned!' because I don't care about them at all
- 3 0 When I want to do something for enjoyment I can find someone to join me if I want to
 1 I am able to do something for enjoyment even when I can't find someone to join me
 2 I loose interest in doing things for enjoyment when there is no one to join me
 3 I have no interest in doing anything for enjoyment when there is no one to join me
- 4 0 I rarely feel jumpy or uptight
 1 I sometimes feel jumpy and uptight
 2 I often feel jumpy or uptight
 3 I feel jumpy or uptight all the time
- 5 0 I know someone nearby who really understands me
 1 I'm not sure there's anyone nearby who really understands me
 2 I'm worried because no one nearby really seems to understand me
 3 I'm extremely disturbed that no one nearby understands me at all
- 6 0 I'm not ashamed to show my anger because it's no worse or better than anyone elses
 1 I'm sometimes afraid to show my anger because it goes up quicker than other people's
 2 I'm often afraid to show my anger because it might turn to violence
 3 I'm so afraid of becoming violent that I never allow myself to show any anger at all
- 7 0 I don't have any past traumas to feel overly anxious about
 1 When something reminds me of my past traumas I feel anxious but can tolerate it
 2 When something reminds me of my past traumas I feel very anxious but can use special ways to tolerate it
 3 When something reminds me of my past traumas I feel so anxious I can hardly stand it and have no ways to tolerate it

- 8 0 I have not re-experienced a flashback to a trauma event ' as if I were there again'
 1 I have re-experienced a flashback to a trauma event 'as if I were there again' for a few minutes or less
 2 My re-experiencing of a flashback to a trauma event sometimes lasts the best part of an hour
 3 My re-experiencing of a flashback to a trauma event often lasts for an hour or more
- 9 0 I am less easily distracted than ever
 1 I am as easily distracted as ever
 2 I am more easily distracted than ever
 3 I feel distracted all the time
- 10 0 My spiritual life provides more meaning than it used to
 1 My spiritual life provides about as much meaning as it used to
 2 My spiritual life provides less meaning than it used to
 3 I don't care about my spiritual life
- 11 0 I can concentrate better than ever
 1 I can concentrate about as well as ever
 2 I can't concentrate as well as I used to
 3 I can't concentrate at all
- 12 0 I've told a family member about the important parts of my most traumatic experiences
 1 I have to be careful in choosing the parts of my traumatic experiences to tell friends or family members
 2 Some parts of my traumatic experiences are so hard to understand that I've said almost nothing about them to anyone
 3 No one could possibly understand the traumatic experiences I've had to live with
- 13 0 I generally don't have nightmares
 1 My nightmares are less troubling than they were
 2 My nightmares are just as troubling as they were
 3 My nightmares are more troubling than they were
- 14 0 I don't feel confused about my life
 1 I feel less confused about my life than I used to
 2 I feel just as confused about my life as I used to
 3 I feel more confused about my life than I used to
- 15 0 I know myself better than I used to
 1 I know myself about as well as I used to
 2 I don't know myself as well as I used to
 3 I feel like I don't know who I am at all

- 16 0 I know more ways to control or reduce my anger than most people
 1 I know about as many ways to control or reduce my anger as most people
 2 I know fewer ways to control or reduce my anger than most people
 3 I know of no ways to control or reduce my anger
- 17 0 I have not experienced any major trauma in my life
 1 I have experienced one or more traumas of limited intensity
 2 I have experienced very intense and upsetting traumas
 3 The traumas I have experienced were so intense that memories of them intrude on my mind without warning
- 18 0 I've been able to shape things toward attaining many of my goals
 1 I've been able to shape things toward attaining some of my goals
 2 My goals aren't clear
 3 I don't know how to shape things towards my goals
- 19 0 I am able to focus my mind and and concentrate on the task at hand regardless of unwanted thoughts
 1 When unwanted thoughts intrude on my mind I'm able to recognise them briefly and then refocus my mind on the task in hand
 2 I'm having a hard time coping with unwanted thoughts and don't know how to refocus my mind on the task in hand
 3 I'll never be able to cope with unwanted thoughts
- 20 0 I am achieving most of the things I want
 1 I am achieving many of the things I want
 2 I am achieving some of the things I want
 3 I am achieving few of the things I want
- 21 0 I sleep as well as usual
 1 I don't sleep as well as usual
 2 I wake more frequently or earlier than usual and have difficulty getting back to sleep
 3 I often have nightmares of wake up several hours earlier than usual and cannot get back to sleep
- 22 0 I don't have trouble remembering things I should know
 1 I have less trouble than I used to remembering things I should know
 2 I have about the same trouble as I used to remembering things I should know
 3 I have more trouble than I used to remembering things I should know
- 23 0 My goals are clearer than they were
 1 My goals are as clear as they were
 2 My goals are not as clear as they were
 3 I don't know what my goals are

- 24 0 I am usually able to let bad memories fade from my mind
1 Sometimes a bad memory comes back to me, but I can modify it, replace it or set it aside
2 When bad memories intrude on my mind I can't seem to get them out
3 I worry that I am going crazy because bad memories keep intruding on my mind
- 25 0 Usually I feel understood by others
1 Sometimes I don't feel understood by others
2 Most of the time I don't feel understood by others
3 No one understands me at all
- 26 0 I have not lost anything or anyone dear to me
1 I have grieved for those I've lost and now can go on
2 I haven't finishing grieving for those I've lost
3 The pain of my loss is so great that I can't grieve and don't know how to get started



3. YOUR ATTITUDES TO DEATH

This questionnaire is concerned with your attitudes towards death. Circle true or false for each question which best represents your feelings.

I am very much afraid to die	TRUE	FALSE
The thought of death seldom enters my mind	TRUE	FALSE
It doesn't make me nervous when people talk about death	TRUE	FALSE
I dread to think about having an operation	TRUE	FALSE
I am not at all afraid to die	TRUE	FALSE
I am not particularly afraid of getting cancer	TRUE	FALSE
The thought of death never bothers me	TRUE	FALSE
I am often distressed by the way time flies so very rapidly	TRUE	FALSE
I fear dying in a painful way	TRUE	FALSE
The subject of life after death troubles me greatly	TRUE	FALSE
I am really scared of having a heart attack	TRUE	FALSE
I often think about how short life really is	TRUE	FALSE
I shudder when I hear people talking about World War III	TRUE	FALSE
The sight of a dead body is horrifying to me	TRUE	FALSE
I feel that the future holds nothing for me to fear	TRUE	FALSE

Please indicate which level of each statement most reflects your views

	Often	Sometimes	Rarely	Never
1 I think about my own death				
2 I think about the death of loved ones				
3 I think about dying young				
4 I think about the possibility of being killed on a city street				
5 I have fantasies about my own death				
6 I think about death just before I go to sleep				
7 I think about how I would act if I knew I were to die within a given period of time				
8 I think about how my relatives would act and feel upon my death				
9 When I am sick I think about death				
10 When I am outside during a lightning storm I think about the possibility of being struck by lightning				
11 When I am in a car I think about the high incidence of traffic fatalities				
	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
12. I think people should first become concerned about death when they are old				
13 I am much more concerned about death than those around me				
14. Death hardly concerns me				
15. My general outlook just doesn't allow for morbid thoughts				
16 The prospect of my own death arouses anxiety in me				
17 The prospect of my own death depresses me				

	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
18 The prospect of the death of my loved ones arouses anxiety in me				
19. The knowledge that I will surely die does not in any way affect the conduct of my life				
20 I envision my own death as a painful nightmarish experience				
21 I am afraid of dying				
22 I am afraid of being dead				
23. Many people become disturbed at the sight of a new grave but it does not disturb me				
24 I am disturbed when I think about the shortness of life				
25. Thinking about death is a waste of time				
26. Death should not be regarded as a tragedy if it occurs after a productive life				
27 The inevitable death of man poses a serious challenge to the meaningfulness of human existence				
28. The death of an individual is ultimately beneficial because it facilitates change in society				
29 I have a desire to live on after death				
30 The question of whether or not there is a future life worries me considerably				

4. YOUR WORK AND COPING STRATEGIES

Please indicate in terms of your own career, the relative importance of each value statement.

	Very important	Important	Of minor importance	Not important
1 Attending funeral association meetings				
2 Close contact with other funeral directors around the region and country				
3 Autonomy in my work; having the freedom and responsibility to do the job in the way I feel it should be done				
4 Reading funeral service literature				
5 The opportunity to work with people rather than things				
6 Continually advancing the knowledge and the skills through reading and formal courses				
7 Working with people who are committed to funeral service as a life career				
8 The chance to help people; to do something worthwhile for society				
9 Making a good deal of money				
10 Successfully managing the commercial affairs of the mortuary				
11 Being a good salesman				
12 Being respected as a good businessman				
13 Social status and prestige in the community				
14 Moving up within this funeral establishment				



1. Please circle to what extent you most or least enjoy the following aspects of your work

	not enjoyable					very enjoyable					
	0	1	2	3	4	5	6	7	8	9	10
Working with the bereaved family											
The business and professional side of your duties											
Embalming and body preparation work											
Organising and conducting the funeral ceremony											

2. Please circle how stressful you regard working with the families of each of the following:

	unstressful					very stressful					
	0	1	2	3	4	5	6	7	8	9	10
Natural deaths											
Accidental deaths											
Suicides											
Murders											
Childhood deaths											

3. Please circle how stressful you regard working with the body of each of the following:

	unstressful					very stressful					
	0	1	2	3	4	5	6	7	8	9	10
Natural deaths											
Accidental deaths											
Suicides											
Murders											
Childhood deaths											

If working with a family or with a body has caused you upset at any time how have others reacted to your need for support. Please tick the appropriate box for each group of people

	very supportive	supportive	neutral	unsupportive	very unsupportive
Family					
Colleagues					
Friends					
Neighbours					
Other. please state					

A number of different professionals e.g police and ambulance drivers etc have to deal with death as a part of their work. Previously they have described the particular aspects they find distressing. Can you please use the space below to describe the stressful and distressing aspects of dealing with the dead, embalming and reconstruction work you have experienced (I should remind you that this information is strictly confidential and is only to be used for the purpose of this research)

Please read each item below and indicate, by circling the appropriate category, to what extent you use it to help coping with stressful or distressing aspects of your work. It may help to think about the example you have described on the previous page. Do not miss any out.

	not used	used somewhat	used quite a bit	used a great deal
1. Just concentrate on what I had to do next - the next step	0	1	2	3
2. I tried to analyse the problem in order to understand it better	0	1	2	3
3. Turned to work or substitute activities to take my mind off things	0	1	2	3
4. I felt that time would make a difference the only thing to do was wait	0	1	2	3
5. Bargained or compromised to get something positive from the situation	0	1	2	3
6. I did something I didn't think would work but at least I was doing something	0	1	2	3
7. Tried to get the person responsible to change his or her mind	0	1	2	3
8. Talked to someone to find out more about the situation	0	1	2	3
9. Criticised or lectured myself	0	1	2	3
10. Tried not to burn my bridges, but leave things open somewhat	0	1	2	3
11. Hoped a miracle would happen	0	1	2	3
12. Went along with fate; sometimes I just have bad luck	0	1	2	3
13. Went on as if nothing had happened	0	1	2	3
14. I tried to keep my feelings to myself	0	1	2	3
15. Looked for the silver lining, so to speak; tried to look on the bright side of things	0	1	2	3
16. Slept more than usual	0	1	2	3
17. I expressed anger to the person(s) who who had caused the problem	0	1	2	3

	not used	used somewhat	used quite a bit	used a great deal
18. Accepted sympathy and understanding from someone	0	1	2	3
19. I told myself things that helped me to feel better.	0	1	2	3
20. I was inspired to do something creative	0	1	2	3
21. Tried to forget the whole thing	0	1	2	3
22. I got professional help	0	1	2	3
23. I changed or grew as a person in a good way	0	1	2	3
24. I waited to see what would happen before doing anything	0	1	2	3
25. I apologized or did something to make up	0	1	2	3
26. I made a plan of action and followed it	0	1	2	3
27. I accepted the next best thing to what I wanted	0	1	2	3
28. I let my feelings out somehow	0	1	2	3
29. I realized I brought the problem on myself	0	1	2	3
30. I came out of the experience better than I went in	0	1	2	3
31. Talked to someone who could do something concrete about the problem	0	1	2	3
32. Got away from it for a while; tried to rest or take a holiday	0	1	2	3
33. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication etc	0	1	2	3
34. Took a big chance or did something very risky	0	1	2	3
35. I tried not to act too hastily or follow my first hunch	0	1	2	3
36. Found new faith	0	1	2	3
37. Maintained my pride and kept a stiff upper lip	0	1	2	3
38. Rediscovered what is important in life	0	1	2	3

	not used	used somewhat	used quite a bit	used a great deal
39. Changed something so things would turn out alright	0	1	2	3
40. Avoided being with people in general	0	1	2	3
41. Didn't let it get to me; refused to think too much about it	0	1	2	3
42. I asked a relative or friend I respected for advice	0	1	2	3
43. Kept others knowing from how bad things were	0	1	2	3
44. Made light of the situation; refused to get too serious about it	0	1	2	3
45. Talked to someone about how I was feeling	0	1	2	3
46. Stood my ground and fought for what I wanted	0	1	2	3
47. Took it out on other people	0	1	2	3
48. Drew on my past experiences; I was in a similar situation before	0	1	2	3
49. I knew what had to be done, so I doubled my efforts to get things done	0	1	2	3
50. Refused to believe it had happened	0	1	2	3
51. I made a promise to myself that things would be different next time	0	1	2	3
52. Came up with a couple of different solutions to the problem	0	1	2	3
53. Accepted it, since nothing could be done	0	1	2	3
54. I tried to keep my feelings from interfering with other things too much	0	1	2	3
55. Wish that I could change what had happened or how I felt	0	1	2	3
56. I changed something about myself	0	1	2	3

	not used	used somewhat	used quite a bit	used a great deal
57. I daydreamed or imagined a better time or place than the one I was in	0	1	2	3
58. Wished that the situation would go away or somehow be over with	0	1	2	3
59. Had fantasies or wishes about how things might turn out	0	1	2	3
60. I prayed	0	1	2	3
61. I prepared myself for the worst	0	1	2	3
62. I went over in my mind what I would say or do	0	1	2	3
63. I thought about how a person I admire would handle this situation and used this as a model	0	1	2	3
64. I tried to see things from the other persons point of view	0	1	2	3
65. I reminded myself how much worse things could be	0	1	2	3
66. I jogged or exercised	0	1	2	3

If there are any further comments you would would like to make relating to the issues raised in this questionnaire please add them below

MANY THANKS FOR ALL YOUR HELP !

SECTION 3: MAJOR RESEARCH PROJECT PAPER

Appendix 1: Notes for authors - 'Mortality'

Appendix 2: The policies and practices of Kenyons Emergency Services

Appendix 3: Qualitative information provided by the sample

Appendix 4: Frequencies of ratings of enjoyment for different aspects of funeral directing work

Appendix 5: Frequencies of ratings of stress of working with families and the different modes of death

Appendix 6: Frequencies of ratings of stress of working with bodies from different modes of death

Appendix 7: Frequencies of ratings of support networks

MORTALITY

Notes for Contributors

Mortality welcomes original contributions from all parts of the world on the understanding that their contents have not previously been published nor submitted elsewhere for publication. All submissions will be sent anonymously to independent referees. It is a condition of acceptance that papers become the copyright of the publisher.

Manuscripts

Manuscripts may be in the form of: (1) research papers (not exceeding 8,000 words); (2) reviews; (3) short reports for rapid publication (not exceeding 2,000 words); or (4) letters to the Editors. Four complete copies should be submitted to the Editors, *Mortality*, School of Cultural and Community Studies, Arts B, University of Sussex, Falmer, Brighton BN1 9QN, United Kingdom.

All submissions should be in the Harvard style (American Psychological Association, *Publication Manual*, Fourth edition, 1994). Papers should be typed on one side of the paper, double spaced (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

The first page should include the title of the paper, name(s) of the author(s), and for each author a short institutional address and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including fax number and e-mail address if possible) of the author to whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain an abstract of not more than 200 words. The third page should repeat the title as a heading to the main body of the text. Within the text section headings and subheadings should be typed on a separate line without numbering, indentation or bold or italic typeface.

References

References should be in the Harvard style. All publications cited in the text should be listed following the text; similarly, all references listed must be mentioned in the text. Within the text, references should be indicated by the author's name and year of publication in parentheses, e.g. (Sloane, 1991) or (Howarth & Jupp, 1995), or, if there are more than two authors, (Boddington *et al.*, 1987). Where several references are quoted consecutively within the text, the order should be chronological, e.g. (Sloane, 1991; Dickenson & Johnson, 1993), or within a single year, alphabetical (Dinnage, 1990; Kellehear, 1990; Williams, 1990). If more than one paper from the same author(s) and year are listed, the date should be followed by (a), (b), etc., e.g. (Walter, 1991a).

References should be listed alphabetically by author on a separate sheet(s) (double spaced) in the following standard form, capitalisation and punctuation:

a) for periodical articles (titles of journals should *not* be abbreviated):
Kselman, T. (1988) Funeral conflicts in nineteenth-century France. *Comparative Studies in Society and History*, 30, 312-332.

b) for books:
Parry, J. P. (1994) *Death in Banaras* (Cambridge, Cambridge University Press).

c) for chapters within multi-authored books:
Young, Sir G. (1981) Hospice and health care, in: C. Saunders, D. H. Summers & N. Teller (Eds), *Hospice: The Living Idea* (London, Edward Arnold).

Illustrations

All illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Fig. 3). Each should be submitted on a separate sheet of paper, numbered on the back with Figure number (Arabic numerals) and the title of the paper. The captions of all figures should be submitted on a separate sheet, should include keys to symbols and should make interpretation possible without reference to the text.

Figures should ideally be professionally drawn and designed with the format of the journal (175 x 248 mm) in mind and should be capable of reduction.

Tables

Tables should be submitted on separate sheets, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

Proofs

Proofs will be sent by air mail to the author nominated for correspondence. Proofs are supplied for checking and making essential typographical corrections, not for general revision or alteration. Proofs must be returned (by air mail or fax) within 72 hours of receipt.

Offprints

Fifty offprints of each paper are supplied free to the nominated author for correspondence for further distribution, together with a complete copy of the relevant issue of the journal. Additional offprints may be purchased and should be ordered when proofs are returned. Offprints are sent approximately two weeks after publication.



CARFAX

APPENDIX 2

THE POLICIES AND PRACTICES OF KENYONS EMERGENCY SERVICES

Kenyons Emergency Services (KES) has been involved in disaster work since the early 1920s. The company has assisted coroners and the police both with major disasters and with other incidents which involve significant fatalities. The main focus of their work is the identification and repatriation of human remains.

Following the announcement of an incident (and KES having been alerted) a 'scout' is sent to the scene to determine what will be needed on site. The field team is then dispatched and can include; forensic odontologists, embalmers, forensic pathologists, and mortuary technicians along with all the necessary equipment. The primary task is the recovery of victims from the wreckage and the site. In most circumstances this is done by the army and police, but sometimes (such as after the Katmandu air disaster) members of KES assist in this work also.

In establishing the identity of the victims all available information is used including property and clothing found on the body and at the site. This work is usually done by the forensic pathologists. The remains of bodies are reconstructed and cosmetically embalmed so that wherever possible a viewing can take place by the family. Personal property is cleaned and repaired whenever possible and returned to the family of the deceased.

Whilst the field team is doing this work on site, the home team collects at the London-based operations room from where they will contact the victim's family or next-of-kin to collect the *ante-mortem* information which will aid in the identification process. As information is collected it is passed to the field team so that evidence and information can be compared. The policy is that each member of the home team has an allotted number of families which they alone deal with.

In this way the family has a known point of contact each time and a supportive relationship and rapport can be established. All relevant information is then collected by the home team and relayed to the field team who use it to establish identification. When a positive match has been established the information from both the family and the field team are then presented to the police who formally confirm identification and inform the deceased's family.

The field team is also accompanied by its administrative team, the Secretariat, which processes all the paperwork required under such circumstances. The Secretariat is supported by the home team who act as liaison between the carrier and government(s) concerned with the field team.

If the disaster has occurred overseas then the repatriation of victims is often requested and this is coordinated by KES's sister company Kenyon Air Transportation and local burial is supported with KES giving instructions to the local agent or the family's nominated funeral director.

APPENDIX 3

QUALITATIVE INFORMATION PROVIDED BY THE SAMPLE

- 001 I don't think I feel any stress or have experienced any distressing aspects dealing with the dead, embalming or/and reconstruction work. I get a good deal of job satisfaction at the end result and 99 times out of 100 the families are more than happy with my work.
- 002 I have never found any aspect of my work distressing.
- 003 Providing a service which assists families and friends, and knowing my standards as a funeral director are high. I feel that I am not stressed by any aspects of my work.
- 004 I find dealing with the family of the deceased can be more stressful and distressing than actually dealing with the deceased - particularly so if a young life has been cut short. Within myself I sometimes feel inadequate in what I can offer in the way of support but at the end of the day if I have "done the job well" that in itself will have helped the bereaved and it also helps me cope.
- 004 Dealing with the deceased, i.e. embalming, reconstructing etc does not distress me and I find it rewarding because I feel confident in what I am doing and know that the family will be able to see their loved one looking as lifelike as possible. The fact that they can do this can help the grief process. Badly mutilated cadavers do not upset me and although I have never had to work in a disaster situation I realise that faced with such a situation my feelings could change.
- 005 The most distressing part of our work is dealing with the children and

youths who have died or been killed, also where a parent has died leaving a young person behind.

006 As a member of Kenyons Emergency Services I have always known that I would one day go to a major accident. Lockerbie was my first. I stayed there for nine days. The stressful part of the job is to complete the work on time. The distressing part is more for other people who are not used to this sort of work and see 100-200 bodies lying about is too much for them to cope with i.e.soldiers and policemen. The effect on me is to get the job done - if reconstructing someones face so that his/her family can look at them and grieve in the normal way - then I have done my job. It does distress me when I know people will not be able to view, but this is distress I can cope with. Bodies without heads being sent back home is a problem. At Lockerbie we made heads from paper to give body bags a shape as if a head was there. If this had not been done yes it would have bothered me a bit but again controllable. In Bangkok more of the bodies could be seen. Because of time taken for us to get there this meant bodies going back to Austria and Germany in an advanced state of decomposition. The embalming stopped the advance of the decomposing but the bodies were to say the least not very nice to work with and to that extent a most unpleasant experience. I do not think that any of us pondered too long about it. We still went out at night and had a laugh. The job cannot be done if you get depressed about it. The work must be carried out and carried out well. If we can send bodies back home for funerals then we are helping the families. It does bother me about the bodies that are never recovered. The families have no focal point and no ending it would seem to their grieving. I do not have nightmares about these crashes, but I do think of them at times. The destruction, loss of life and disfiguration is too much for some people to take in even for embalmers, but the job has to be done. A friend of mine who has been to many many of these incidents including the Falklands was overcome when he returned to Lockerbie to the garden of remembrance, he had to

be on his own and was happy at having these feelings it did mean that he was human. When I pass Lockerbie I seem drawn to the place and have been back to the Town Hall (mortuary). It felt good that the basement had been filled in and was being used for local events.

006 (In response to 65 on coping inventory) I don't think things could have been much worse than Lockerbie. The only way we could deal with it is that we (as a team) are always ready for these accidents to happen. Some people I know will say if they hear of a crash "are you going to that one" they have no conception.

008 It occasionally becomes slightly distressing when dealing with infant deaths.

012 As I have not been involved in the funeral business for all that long, my experiences are fewer than other people's (probably). I have found just road accident victims are the cases which I think about more and obviously find distressing. I recently removed a blackened skeleton from an accident and this caused a bit of stress. Not knowing what is waiting for you when called to a road accident is sometimes worse than actually dealing with it. On the other hand most of the cases dealt with in these situations were not known to me as living people as is the case with most natural deaths in the town.

013 Having to deal with young children always gets to me. Having two children of my own I feel very protective towards them both. Suicides I find very stressful to deal with, what can you say to a young mum or wife? I find that I just tend to close a door and be by myself. The most distressing case was when a nine year old boy fell into a turnip machine on his dad's farm four years ago. I just cannot forget that boy or his parents.

- 014 None really by nature I am a very detached person. 'On call' is probably the most stressful part of my job, working a normal day then being available at all hours etc feeling tired not being able to concentrate.
- 016 I find the most stressful part of the job is to make sure the arrangements that are going according to plan, make sure the cars are on time, Ministers or Priests turn up for the service, making sure the family are okay on the day of the service. The most distressing part of my duties is to deal with a young child. Over the years I have dealt with a number of children's funerals and have never been able to adjust to how the families are feeling. I carry out the funeral to the best of my ability and hope the work I have done is (sic) been to the satisfaction of the families concerned.
- 020 Thankfully many families have to arrange very few funerals, (even only one) through their lifetime and they are entrusting the funeral director to care for their loved one and provide the best possible service. The most stressful aspects are usually at the initial meeting with the family which may be very soon after the death. There can easily be ten people who are awaiting (sic) when you arrive at the house and you have to take charge and give the best possible advice to enable them to make the best decisions. A funeral director can within a matter of half an hour be sitting in the office doing bookwork to being asked to arrange three funerals (instant stress). People die all over the world and we have to be able to assure the family that nothing is any trouble. Every arrangement has its elements of stress but the elements of stress are greatly increased when dealing with suicides, murders, child deaths, accidents, etc. On many of these arrangements it can be very difficult to get a positive response to questions and it may take several visits before one can truly gauge what the family (and if possible what the bereaved) would wish for e.g. burial or cremation. These arrangements must not be rushed as there are many families who regret decisions that were quickly taken. I am not personally involved in reconstruction.

- 021 Dealing with children, teenagers and my own family members I have found difficult. The sight of my own aunt resting in our embalming room was unpleasant and it took me a while to enter the room on my own. I feel the same way with youngsters and infants, but it's something I try to handle in a professional manner. Also when I was going through my divorce, I found myself more upset than usual.
- 022 I try to distance myself from any trauma and concentrate my efforts in preparing the deceased in order that the bereaved may be able to view the deceased in such a way that they will be able to recall a more pleasant vision which may not have been possible if the identification had been traumatic.
- 050 I hope you can make sense of the last section (coping scale). It does not have any relevance to me personally. The job is there to be done, if you have any doubts or fears then change your occupation.
- 051 The difficulty is trying to work as a professional whilst having absolute compassion for the unfortunate situation. You know that you can't let yourself become too drawn into the emotions, but the danger is you become too clinical and detached as a consequence. You almost have to pretend the situation is not real whilst keeping your mind and both feet firmly on the ground.
- 052 Dealing with the actual body is no problem whatever the situation, whether in the disaster mortuary or at the funeral home. Dealing with families at the disaster site is the most stressful side of my job as a whole.
- 052 The Kenyons Emergencies Services team are my greatest allies and defence of depression in disaster situations, which are my stressful times. We are (the core of the team) more like family, I love and care for them very deeply, we have a bond hard for outsiders to define and understand.

My normal day job as the manager of a funeral home brings pressure quite different (sic). My colleagues who I term as friends are very supportive and I count myself as very lucky I am very happy in all aspects of my working life.

053 Dealing with young adult deaths, When children are orphaned very young.

APPENDIX 4

Frequencies of ratings of enjoyment for different aspects of funeral directing work.

ASPECTS OF WORK	0	1	2	3	4	5	6	7	8	9	10
Working with bereaved family (n=23)	0	0	0	1	0	0	1	2	3	4	12
Business and professional side of duties (n=23)	0	0	0	0	0	1	2	5	4	2	9
Embalming and body preparation work (n=23)	0	1	0	0	0	3	6	1	4	2	6
Organising and conducting the funeral ceremony (n=23)	0	0	0	0	0	0	1	1	5	1	15

0=not enjoyable 10=very enjoyable.

APPENDIX 5

Frequencies of ratings of stress of working with families and the different modes of death.

STRESS OF WORKING WITH FAMILIES	0	1	2	3	4	5	6	7	8	9	10
Natural deaths (n=23)	5	5	4	0	0	5	2	2	0	0	0
Accidental deaths (n=23)	3	0	3	1	1	2	1	2	3	5	2
Suicides (n=23)	2	0	2	1	0	2	1	3	1	6	5
Murders (n=22)	3	0	1	1	0	1	2	2	1	2	8
Childhood deaths (n=23)	1	0	1	1	0	3	1	1	2	2	11

0=unstressful, 10=very stressful

APPENDIX 6

Frequencies of ratings of stress of working with bodies from different modes of death.

STRESS OF WORKING WITH BODIES	0	1	2	3	4	5	6	7	8	9	10
Natural deaths (n=23)	9	3	3	2	5	0	0	1	0	0	0
Accidental deaths (n=23)	6	3	4	0	0	0	1	4	2	2	1
Suicides (n=23)	5	3	4	0	0	1	0	2	5	1	2
Murders (n=22)	5	2	4	1	0	0	0	2	3	0	5
Childhood deaths (n=23)	1	0	4	2	0	2	1	0	2	0	9

0=unstressful, 10=very stressful

APPENDIX 7

Frequencies of ratings of support networks.

SOURCES OF SUPPORT	Very Supportive	Supportive	Neutral	Unsupportive	Very Unsupportive
Family (n=19)	10	7	1	0	1
Colleagues (n=20)	7	9	3	0	1
Friends (n=19)	3	6	9	0	1
Neighbour (n=19)	1	3	13	1	1
Others (n=7)	1	1	4	0	1

SECTION 4: SMALL SCALE EVALUATION PROJECT

Appendix 1: Authors Notes - 'The Journal of Reproductive and Infant Psychology'

Appendix 2: Information leaflet given to Women

Appendix 3: Letter 1

Appendix 4: Letter 2

Appendix 5: Letter 3

Appendix 6: Project Questionnaire

Appendix 7: Proposed Flow Diagram Information Sheet for Women

Notes for Contributors

The *Journal of Reproductive and Infant Psychology* welcomes reports of original research and creative or critical review articles which make an original contribution. Articles should not currently be submitted for publication elsewhere.

Topics of interest to the journal include medical, behavioural, cognitive, affective, dynamic, psychological, societal and social aspects of: fertility and infertility; menstruation and menopause; pregnancy and childbirth; antenatal preparation; motherhood and fatherhood; neonatology and early infancy; infant feeding; early parent-child relationships; post natal psychological disturbance and psychiatric illness; obstetrics and gynaecology including preparation for medical procedures; psychology of women.

The journal also publishes brief reports, comment articles and special issues dealing with innovative and controversial topics. A review section reports on new books and training material.

Studies of both human and animal subjects are welcome.

Papers should be sent in the first instance to one of the joint Editors, or in the case of contributors from the Americas or mainland Europe, to the appropriate regional Associate Editor.

Anne Walker, Dept of Psychology, The University, Dundee, DD1 4HN, UK;

David Messer, Psychology Division, University of Hertfordshire, Hatfield, Herts AL10 9AB, UK;

Donna Stewart, Dept of Psychiatry, St Michael's Hospital, 30 Bond Street, Toronto, Ontario, Canada M5B 1W8;

Dieter Wolke, Dr Von Haunersches Children's Hospital, University of Munich, Lindwurmstrasse 4, D-8000 Munich 2, Germany.

Contributions should be as concise as possible and should not normally exceed 5000 words or the equivalent lineage including tables and figures. The title should be brief but precise. Each paper should be accompanied by an abstract of not more than 200 words.

Papers should be typed on A4 or equivalent paper, on one side, double spaced with margins of not less than 3.5 cm. Sheets should be numbered consecutively at the head. The top copy and two good copies should be submitted.

Papers are refereed anonymously. The author's name and address should therefore appear under the title on a separate page. The title and abstract should appear on the first page of text. Authors who wish to ascertain in advance the criteria on which submissions are judged may obtain a copy of the blank referee's form from the editors.

Tables should be typed double spaced on separate sheets, or spaced sufficiently to be distinct in the case of small tables. They should be numbered in sequence in arabic numerals and referred to in the text as 'Table 1' etc. Large tables of more than six lines should be titled in order to make the contents comprehensible independently of the text.

Diagrams, graphs, drawings and half-tone illustrations should be on a separate sheet labelled 'Fig. 1' and so forth. Each sheet should carry at the top the title of the article. Where possible they should be submitted as artwork ready for photographic reproduction, larger than the intended size. Where more than one figure is submitted, they should as far as possible be to the same scale. When submitting articles on disc (see below) figures should be supplied as separate TIFF or EPS files if possible.

References in the text should cite the author's name followed by the date of publication unless there are more than two authors where only the first author's name should be given followed by '*et al.*'. References should be listed at the end of the paper in alphabetical order by first author, but including all authors, in the following format with titles of articles, books and journals given in full.

Farrant, W. (1985) 'Who's for amniocentesis?' The politics of prenatal screening. In: Homans, H. (Ed.) *The Sexual Politics of Reproduction*, pp. 96-177. Gower, London.

Harper, P.S. (1991) *Practical Genetic Counselling*. Third edn. Butterworth-Heinemann, Oxford,

Robinson, A., Bender, B.G. and Linden, M.G. (1989) Decisions following the intrauterine diagnosis of sex chromosome aneuploidy. *American Journal of Medical Genetics*, 34: 552-554.

SI units should be used for all measurements. Imperial measurements may be quoted in brackets. Where studies involve small numbers of subjects, both numbers and percentages of groups should be given.

Authors are advised to avoid sexist sentiments and language, except in so far as these form part of a study.

After notification of acceptance of a paper, authors should, if possible, send a copy of the final version in PC format as a word-processed document on a 3.5" or 5.25" floppy disc (Apple-Macintosh formats can be accepted, but not Amstrad's Locoscript on CF2 discs) to the accepting editor.

Page proofs will be sent to the author submitting each article. Correction of typographical and other minor errors only will be permitted at this stage. Textual alterations may be charged to authors in exceptional circumstances.

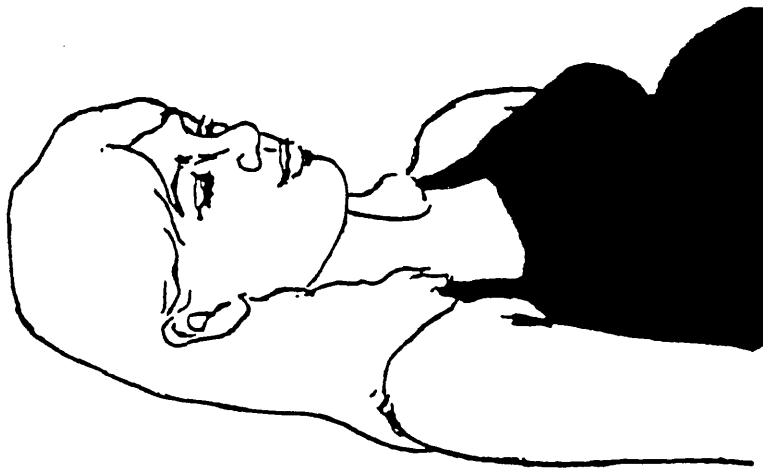
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THE SCREENING TEST FOR SPINA BIFIDA AND DOWN'S SYNDROME



Leaflet produced by:

THE WEST OF SCOTLAND PRENATAL SCREENING
SERVICE

DUNCAN GUTHRIE INSTITUTE OF MEDICAL GENETICS
YORKHILL
GLASGOW

August 1991

FOLLOW-UP TESTS WHICH MAY BE DONE

REVIEW OF PREGNANCY DATES: New information may be obtained about the age of the baby. This may show that the pregnancy is either not as far along or is further along than was thought. If so the results may be normal for this stage of pregnancy and no more tests are needed.

REPEAT BLOOD TEST: Sometimes the blood test is repeated. If the repeat test is negative no more tests are usually needed.

ULTRASOUND: This test uses sound waves to make a picture of the baby on a special TV screen. It can show the age and position of the baby, and also if there are twins. It may also detect abnormalities or other problems.

AMNIOCENTESIS: For most women amniocentesis takes only a few minutes and causes little discomfort. First ultrasound is used to locate a safe place in the uterus. Then a needle is inserted through the woman's abdomen into the fluid around the baby. A small amount of fluid is taken out and sent to the laboratory for AFP and chromosome testing. The AFP results are usually available in a week and the chromosome results in 2-3 weeks.

There is a very small risk of miscarriage following amniocentesis.

NOT EVERYONE WILL NEED ALL THE FOLLOW-UP TESTS

IF THE TESTS SHOW THAT THE BABY HAS AN ABNORMALITY

Your doctor will provide information about the type of abnormality that has been found and how it may affect the baby. If a serious abnormality is found the parents may choose to end that pregnancy and try for an unaffected child at another time.

Please contact your doctor or midwife if you have any queries or concerns about the results of your tests.

SOME INFORMATION ABOUT THIS

TEST

As part of your antenatal care you can choose to have a test which measures the amount of two substances called AFP and HCG, which naturally appear in the mother's blood during pregnancy.

Variation in the level of AFP and HCG can give information about two types of abnormality which may occasionally occur in the baby - **spina bifida** and **Down's syndrome**.

With some pregnancies the level of AFP may be higher than normal and this may indicate that there is an increased risk of spina bifida.

The HCG Level may also vary from normal and this, combined with the AFP level, may indicate that there is an increased risk of Down's syndrome.

Most women with these results, will have normal healthy babies. Follow-up tests may be needed however to check whether an abnormality is present or not.

Not all abnormalities will be found by this screening test.

The test is carried out on a blood sample taken at around the 16th week of pregnancy.

A "POSITIVE-HIGH" AFP RESULT

The most common causes are :

- The pregnancy is further along than was thought.
- There are twins.
- Normal variations in the level of AFP in the blood.

Occasionally, a high AFP result means that the baby has an abnormality, or there is a pregnancy complication.

A HIGH AFP BLOOD TEST BY ITSELF DOES NOT DETECT AN ABNORMALITY.

FOLLOW-UP TESTS ARE NEEDED TO EXPLAIN WHY THE AFP RESULT WAS HIGH.

MOST WOMEN WITH THESE RESULTS HAVE NORMAL HEALTHY BABIES.

ABNORMALITIES WHICH MAY BE FOUND THROUGH FOLLOW-UP TESTING.

Neural tube defects - the two main kinds of neural tube defect are *spina bifida* and *anencephaly*.

Babies with **spina bifida** have an opening in the bones of the spine. Usually the opening is not covered by skin and the nerves which control the lower part of the body are exposed and damaged. This can cause some or all of the following problems: weak or paralysed lower body, bladder and bowel problems, deformed legs or spine, hydrocephalus (water on the brain), mental handicap.

Babies with **anencephaly** have a large part of the skull missing and the brain is not properly formed. They die before or very soon after they are born.

Abdominal wall defects - these are abnormal openings in the abdomen. Intestines and sometimes other organs are outside of the body. In many cases surgery can correct the defect.

A "POSITIVE-HIGH" HCG RESULT

The most common causes are :

- The pregnancy is not as far along as was thought
- Normal variations in the level of HCG in the blood.

Occasionally, a high HCG result means that the baby has an abnormality.

THIS TYPE OF POSITIVE RESULT BY ITSELF DOES NOT DETECT AN ABNORMALITY.

FOLLOW-UP TESTS ARE NEEDED TO EXPLAIN WHY THE HCG RESULT WAS HIGH.

MOST WOMEN WITH THESE RESULTS HAVE NORMAL HEALTHY BABIES.

ABNORMALITIES WHICH MAY BE FOUND THROUGH FOLLOW-UP TESTING.

The most serious defects are **chromosomal disorders**.

Chromosomes carry genes which pass certain characteristics from parents to their children. Abnormalities occur when there are too many or too few chromosomes or there is a defective chromosome.

Down's syndrome is the most common chromosomal disorder.

People with **Down's syndrome** have an extra chromosome, having three copies of chromosome number 21 instead of two. They will have a learning disability (mental handicap) and may have other abnormalities such as heart defects.

The Queen Mother's Hospital

Our Ref:
Your Ref:
Enquiries to:



YORKHILL
GLASGOW G3 8SJ

Telephone: 041-201 0550 QMH

DATE AS POSTMARK

Dear

You will be pleased to know that the result of your recent blood test shows that you are at LOW RISK of your baby having Spina Bifida or Down's Syndrome. No further testing is indicated.

Yours sincerely,

Registrar.

The Queen Mother's Hospital

Our Ref: ---/CF

Your Ref:

Enquiries to: Ext: 0574



YORKHILL
GLASGOW G3 8SJ
Telephone: 041-339 8888

*

Mrs *

Dear Mrs *

Your recent AFP test has come back showing a raised result and we would like to perform another scan on your baby. To save you any unnecessary worry, I would like to point out that raised results may be associated with minor problems and can often occur in completely normal pregnancies.

An appointment has been arranged for you to attend our Ultrasound Department on *, when a detailed scan of the baby will be carried out.

Yours sincerely

*

*

cc: Dr *

LOW 111 2712 2 APPENDIX 5
/CF

Ext: 0574

*

*

Dear Mrs *

We have received the results of your recent screening AFP/HCG blood test. We would like to see you at the Ultrasound Department in the Queen Mother's Hospital to discuss this further.

An appointment has been made for you to attend on * at *

Yours sincerely

*

*

cc: Dr *

APPENDIX 6

PARENTAL INFORMATION SHEET

PRIVATE AND CONFIDENTIAL

STUDY OF WOMEN UNDERGOING SERUM SCREENING

The aim of this study is to find out about your experiences at this clinic regarding serum screening. The results of this study will help to inform us of our practices and make any changes. The following questionnaire asks you a variety of things about yourself, the serum screening you are having and your experience at this clinic. If you have any questions when you have completed the questionnaire a member of staff will be available to answer them for you.

I would like to stress that the information given in this questionnaire will be treated in the strictest confidence and will not be seen by anyone other than myself.

The questionnaire has three parts:

- 1. Questions about you and your background**
- 2. The Prenatal Screening Knowledge Questionnaire**
- 3. Questions about the clinic**

If you have any queries or questions about the study please contact me:

Anna-M Wroblewska,
Dept of Psychological Medicine,
Mental Health Unit,
Gartnavel Royal Hospital,
Glasgow.

SECTION 1: YOU AND YOUR BACKGROUND

In this series of questions please either fill in or circle the appropriate answer.

1. How old are you? _____
2. Have you had at least one previous child? YES NO
3. Was it at this hospital? YES NO
4. How many weeks pregnant are you? _____ WEEKS
5. Have you had any form of serum prenatal screening as yet in this pregnancy?

YES NO UNSURE
6. Have you had serum screening before? YES NO UNSURE
7. Where has the information you have about serum screening come from?
 (tick those which are appropriate)

Leaflet from hospital	<input type="checkbox"/>
Talking with Doctor at the hospital	<input type="checkbox"/>
Talking with GP	<input type="checkbox"/>
Talking with other women	<input type="checkbox"/>
Books and magazines	<input type="checkbox"/>
None	<input type="checkbox"/>

SECTION 2: KNOWLEDGE QUESTIONNAIRE

1. Which of the following have you heard of and/or expect Please answer for each test.

	Heard of	Not heard of	Expect it	Don't expect it	Don't know
Urine tests					
Blood tests					
Blood pressure check					
Scans/Ultrasound					
Tests for spina bifida					
Test for Down's syndrome					
Amniocentesis					
CVS					

Please answer the following questions by ticking **one or more** of the boxes beside each one.

2) Who is routinely offered screening for spina bifida?

- a Women with a family history of spina bifida
- b Older women
- c All pregnant women
- d Don't know

3) Who is routinely offered screening for Down's syndrome?

- a Women with a family history of Down's syndrome
- b Older women
- c All pregnant women
- d Don't know

4) If screening for spina bifida gives an abnormal result what would be likely to happen next?

- a Another scan would be arranged
- b Amniocentesis would be offered
- c CVS would be offered
- d The baby would be treated soon after birth
- e Termination of the pregnancy would be offered as an option
- f Don't know

5) If screening for Down's syndrome gives an abnormal result what would be likely to happen next?

- a Another scan would be arranged
- b Amniocentesis would be offered
- c CVS would be offered
- d Termination of the pregnancy would be offered as an option
- e Don't know

6) Amniocentesis is used to test for?

- a Diabetes
- b Down's syndrome
- c Spina bifida
- d Cerebral palsy
- e Don't know

7) CVS is used to test for?

- a Diabetes
- b Down's syndrome
- c Spina bifida
- d Cerebral palsy
- e Don't know

8) Apart from checking the age and growth of the baby what is the main use of ultrasound scans in pregnancy?

- a To make sure that the baby is alright
- b To see what sex the baby is
- c To test for blood disorders
- d To look for abnormalities
- e Don't know

9) During pregnancy when are the main tests to see if the baby is likely to have spina bifida or Down's syndrome carried out?

- a Before 15 weeks
- b Between 15 and 21 weeks
- c Between 21 and 28 weeks
- d After 28 weeks
- e At any time during pregnancy
- f Don't know

8) A raised AFP (alpha-fetoprotein) could mean:

- a Twins
- b Spina bifida
- c High blood pressure
- d Down's syndrome
- e Normal variation
- f Don't know

SECTION 3. YOUR EXPERIENCE OF THE ANTENATAL CLINIC

The following questions are about your experience of the antenatal clinic so far. Please circle the answer you feel is most appropriate to your case.

1. Were you told what the screening was for?

YES NO UNSURE

2. Were you told the likelihood of Down's syndrome being detected?

YES NO UNSURE

3. Were you told about how the screening will be done?

YES NO UNSURE

4. Were you told what a positive result means?

YES NO UNSURE

5. Were you told what a negative result means?

YES NO UNSURE

6. Were you told what will happen if the result is positive?

YES NO UNSURE

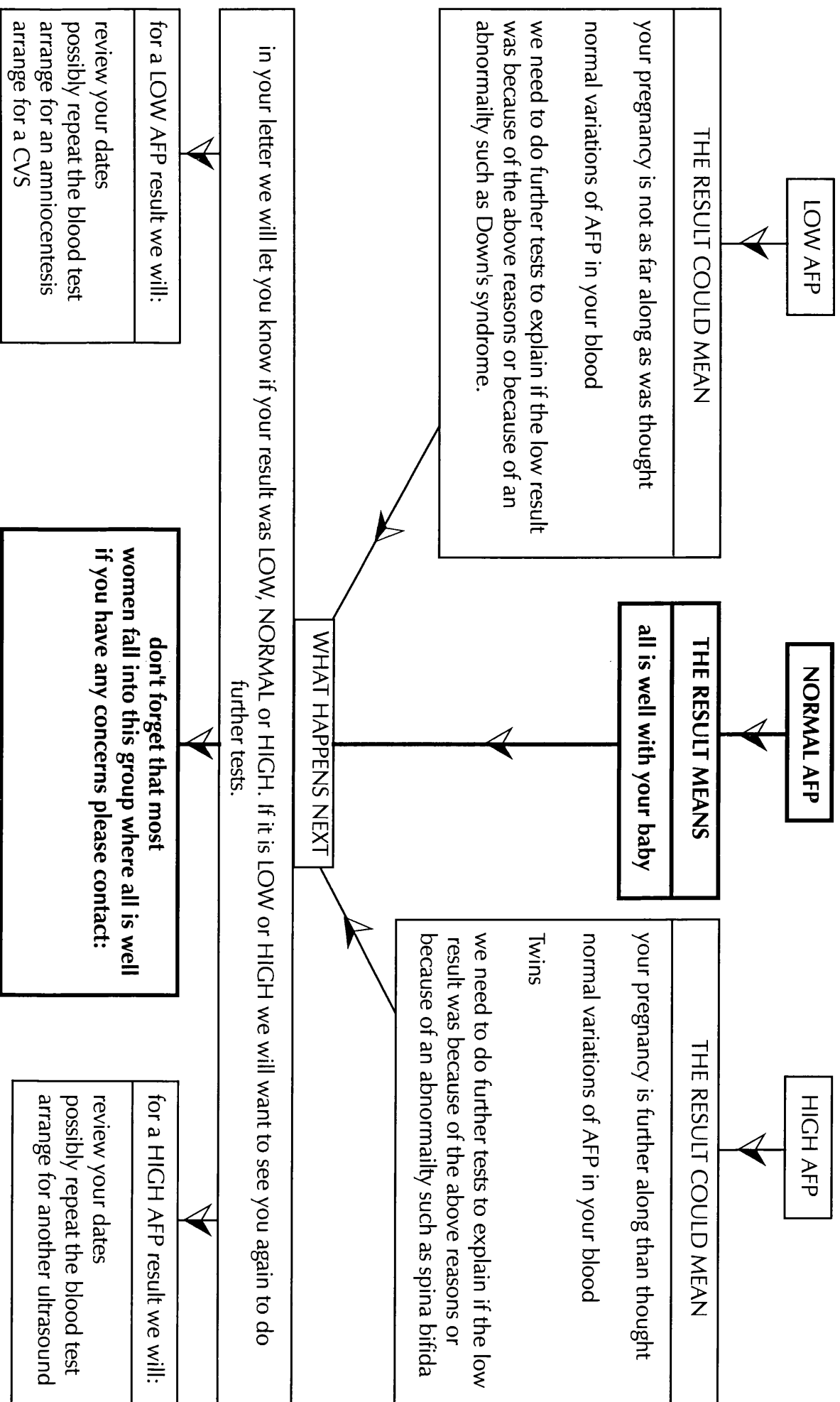
7. Were the options of what happens next after the test discussed?

YES NO UNSURE

8. Were you told how to get any more information if you wanted it?

YES NO UNSURE

Now you have had the AFP test. We will be contacting you with a letter in about two weeks with the results. There are three different types of result which have different meanings. This diagram should help you understand what the results mean and what happens next.



SECTION 5: SINGLE CLINICAL CASE RESEARCH STUDIES

Appendix 1: Authors Notes - 'Behavioural and Cognitive Psychotherapy'