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UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE

Primary Care and Population Sciences

**A Conversation Analytic Examination of
Cancer Helpline Talk**

BY

Catherine Jane Woods

Thesis for the degree of Doctor of Philosophy

December 2016

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF MEDICINE

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A CONVERSATION ANALYTIC EXAMINATION OF CANCER HELPLINE TALK

By Catherine Jane Woods

Cancer is a widespread and feared disease and a leading cause of morbidity and mortality worldwide. Those 'affected' by cancer report a range of immediate and long-term supportive care needs and are increasingly turning to a range of health services to address them, including cancer helplines. Cancer helplines are recognised as integral aspects to the delivery of cancer care and are highly valued by the people who use them but there is little empirical evidence about *how* participants discuss the caller's problems during the calls, despite the well-known communication challenges associated with talking about cancer in other settings. This research examined a large collection (n=99) of 'real-time' audio recorded cancer helpline calls and used Conversation Analysis (CA) to understand the interactional process of seeking and delivering telephone-based cancer care in more detail.

I first provide a quantitative overview of caller requests for assistance and the ways in which these requests were managed by call-handlers. This overview shows that callers telephoned the helpline to request information, advice and psychosocial support about a range of medically-related matters; that most callers volunteered two or more concerns throughout the calls; and that some of these concerns were outside the remit of the call-handlers' expertise. Call-handlers typically provided assistance in the form of verbal information and they also signposted callers onto other healthcare professionals. I then qualitatively explored: 1) a subset of problem presentations (n=23) in which troubling symptoms were topicalised by the caller; 2) a collection (n=11) of calls about the patient's prognosis; and 3) the practices used to bring the calls to a close (n=97).

Overall, this conversation-analytic examination led to greater understandings about the complex problems discussed on cancer helplines and how they were managed.

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DECLARATION OF AUTHORSHIP

I, Catherine Jane Woods, declare that this thesis entitled 'A Conversation Analytic Examination of Cancer Helpline Talk' and the work presented in it are my own, and have been generated by me as the result of my own original research. I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Part of this work has been published before as:

Woods, C.J., Drew, P. & Leydon, G.M. (2015) Closing Calls to a Cancer Helpline and Expressions of Caller Satisfaction. *Patient Education & Counselling*, Vol. 98, pp. 943-953.

- Part of this research has been presented at peer-reviewed conferences before as:

Oral Presentations:

2016 Society for Academic Primary Care South West Meeting, Cardiff, UK.
'A Conversation Analytic Examination of Cancer Helpline Talk: Research Summary'.

- 2016 Faculty of Medicine PhD Conference, Southampton, UK. ‘A Conversation Analytic Examination of Cancer Helpline Talk: Summary of Thesis Findings’.
- 2015 The Helplines Partnership Communication Workshop, London, UK. ‘Bringing Cancer Calls to a Close and Expressions of Caller Satisfaction’.
- 2015 Conversation Analysis and Clinical Encounters (CACE), Loughborough, UK. ‘Requests for a Prognosis on a Cancer Helpline’.
- 2015 Conversation Analysis and Clinical Encounters (CACE), Loughborough, UK. ‘Bringing Cancer Calls to a Close and Expressions of Caller Satisfaction’.
- 2015 Faculty of Medicine PhD Conference, Southampton, UK. ‘A Conversation Analytic Examination of Cancer Helpline Talk: Caller Presentations of Symptom Concerns’.
- 2014 International Conference of Conversation Analysis (ICCA), Los Angeles, USA. ‘Prognosis and the Future’.
- 2013 Conversation Analysis and Clinical Encounters (CACE), York, UK. ‘Bringing Calls to a Close on a Cancer Helpline’.
- 2013 Faculty of Medicine PhD Conference, Southampton, UK 2013. ‘A Conversation Analytic Examination of Cancer Helpline Talk: Research Summary and Call Closings’.

Poster Presentations:

- 2014 NIHR School for Primary Care Research Showcase, Oxford, UK. ‘A Conversation Analytic Examination of Cancer Helpline Talk: Caller Presentations of Symptom Concerns’.
- 2012 NIHR School for Primary Care Research Trainees Event, Oxford, UK. ‘A Conversation Analytic Examination of Cancer Helpline Talk: Research Overview.’

Signed:.....

Date:

Acknowledgements

I would first like to thank Macmillan for agreeing to take part in this research, and the call-handlers and callers who allowed me to listen to their calls - without them this work would not have been possible.

I would also like to thank the National Institute for Health Research (NIHR) and the School for Primary Care Research (SPCR) for funding this PhD studentship.

I am indebted to both of my supervisors, Dr. Geraldine Leydon and Prof. Paul Drew, for their continued support and guidance throughout this PhD journey. Thank you Gerry for being an amazing mentor and for being so kind and funny during this whole experience - your encouragement definitely pulled me out of those dark PhD moments. Thank you Paul for first teaching me the many wonders of conversation analysis and inspiring me to continue with my studies. I have learned a lot from working with you. Thank you both for devoting your time to me and this research and for your patience when reading the many (!) versions of my chapters ("*Catherine I'm not sure this is a word...*").

I was warmly welcomed into the Department of Primary Medical Care by the lovely team of research staff, administrators and PhD students who work there. Thank you for being great office companions and for making the move 'Down Sarf' so much easier. A very, *very* special thanks goes to: Sarah 'Tonkerino' Crine, 'Sir' Andrew Penn, Rosie 'Eddy' Stanford, Lily 'Tiny Tim' Lai, Ingrid 'Inki' Muller and Jenny 'McPotato'-Sharry for their friendship, laughs and many wine-fuelled dinners.

Thank you also to Alex Oldman for dragging me away from my desk to get some Vitamin D and for filling my spare time with lots of excitement and happiness.

Thank you to Dr. Rebecca Barnes and Dr. Lisa Roberts for an encouraging and stimulating viva examination.

Finally, to my weird and wonderful family: Mum, Dad, Anna, Jennie, Ann, Grampse, Nan, Nanny, Nellie and Elsie. Thank you for your generosity, for always being there and for reminding me about the important things in life. Thank you for supporting my decisions to carry on with my studies and for your patience when dealing with the many trials and tribulations of being an eternal student (let's not mention the vegan phase...). I hope you all know how much I love you and how much I owe you for getting this far.

Chapter 1: Introduction

1.1 Introduction

Over the past half a century, but especially within the last twenty years, the helpline industry has grown exponentially (The Helplines Partnership, 2014a; 2014b; 2014c). Helplines are confidential and impartial services that provide “help” in the form of information, advice and (emotional and psychosocial) support, or onward referral over the telephone (usually for free). A central feature of these organisations is that callers and call-handlers talk through the caller’s problems, often with an aim to come to some sort of resolution or outcome that will enable the caller to manage these difficulties on their own after the call (Baker, Emmison & Firth, 2005). The first UK helpline was established in 1953 – a support service called the Samaritans that offered free counselling and support to vulnerable people who were considering committing suicide. The premise for this organisation was based on the idea that the simple act of listening and offering non-judgemental support was the key to alleviating many of the callers’ problems, including the perceived need to end their lives (Samaritans, 2015). There are now approximately 1500 helplines currently in operation in the UK, each of which are wide-ranging in scope and subject matter but many offer assistance on enquiries relating to health and medicine, finance, emotional well-being, computer technology, relationships and various forms of addiction (The Helplines Partnership, 2015). The rapid increase in helpline services signals a growing demand for the provision of assistance over the telephone.

Within this large number of helplines, a study conducted in 2013 identified 95 services that offer supportive care to people affected by cancer (partners, friends and relatives as well as cancer patients) (Leydon & Danquah, 2013). Cancer is a difficult disease to deal with, both physically and emotionally, and many people report high levels of distress, confusion and fear as they go through different stages of the illness (Holland *et al.*, 2010; Clinton-McHarg *et al.*, 2014). Cancer helplines are recognised as an integral aspect to the delivery of cancer care (DoH, 2010; 2011) and they are highly valued by the people who use them (Venn *et al.*, 1996; Byers, Vezina & Campbell, 2002; Montazeri *et al.*, 1999; DoH, 2010), but there is little evidence about how

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callers and call-handlers talk through the many problems associated with this disease *during* the calls. The provision of different health services pose their own unique challenges which need to be understood to ensure users are getting the supportive care they need and to ensure staff feel well-equipped to provide it.

The aim of this research is to fill this evidence gap by focussing on how telephone-based cancer support is sought and delivered on a leading national cancer helpline in the UK called Macmillan Cancer Support (hereafter MCS). The focus on communication will lead to a greater understanding of how problems arising from a diagnosis of cancer are discussed and resolved (or not) which could be used to inform the delivery of cancer telephone services in the future. This thesis is embedded in a broader programme of research that aimed to map a current understanding of cancer helplines in the UK. The broader programme was designed as a mixed methods study and incorporated four elements: 1) a survey of UK helpline services to understand their role(s) and the major challenges they face; 2) qualitative interviews with callers who use specialist helplines to understand their experience of using such services and interviews with call-handlers to elicit their views about providing telephone-based support; 3) expert panels with key stakeholders to generate their perspective about the precursors to miscommunication associated with helpline work and their views about implementing communication training packages for helpline staff; and 4) audio recordings of real-time cancer helpline calls to understand the interactional process of seeking and delivering telephone-based cancer support. Parts of this broader helpline study have been published elsewhere including: a cancer services directory (Leydon & Danquah, 2013), two qualitative studies about the experience of using cancer helplines from the perspective of callers and call-handlers (Ekberg *et al.*, 2014; Leydon *et al.*, in preparation) and two conversation-analytic studies about how the calls are opened (Leydon, Ekberg & Drew, 2013) and how call-handlers obtain information about the callers' ethnicity (Leydon, *et al.*, 2013).

In this introductory chapter I will provide the background and rationale for a conversation-analytic examination of cancer helpline talk by focussing on the complex nature of cancer and the various (practical, medical, emotional) problems associated with a diagnosis (for patients and their family/friends);

the role of information and communication in supporting cancer patients and their families through various stages of the illness; and the role of cancer helplines in the provision of this care. First, a brief outline of cancer as a disease/illness.

1.2 What is cancer?

“Cancer” is the name ascribed to over one hundred diseases, each of which are characterised by abnormal cell growth. All living organisms, from common plants to amphibians to humans, are made up of cells; they are the building blocks of life. Some organisms comprise a single cell, such as yeast; but most others, including the human body, comprise many (trillions) more (James, 2011; CRUK, 2014a; Macmillan Cancer Support, 2015c). A lump of human tissue the size of a sugar cube, for example, contains approximately one thousand million cells, with each one performing its own task to keep the body functioning and working properly (Rees 2004, p. 4). Over time, cells that have become damaged with wear and tear and age are replaced with new ones through a process called “mitosis” (when an existing cell divides in two to create new ones). In a normally functioning body this process is slow, and there is a harmonious balance between cells that are dying and cells that are dividing. Sometimes, however, this balance is out of sync and cells begin to behave in an abnormal fashion, exceeding their usual life span and causing damage to other structures in the body. This abnormal cell growth can lead to a mass of excess cells called a tumour. Some tumours are benign and require basic medical treatment to remove them; while others are malignant and called cancer. Distinguishing features of cancerous tumours include: their ability to spread and destroy other parts of the body from the primary infected area (known as “cancer metastasis”); their ability to grow a new blood supply (thus avoiding destruction by the immune system); and their ability to return in the future after invasive treatments (known as “cancer recurrence”) (McReady & MacDonald, 2006; James, 2011; WHO, 2015).

Cancers are classified into six main groups, as the following table shows.

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Table 1: Classification of different cancer types

	Primary classification	Origin of the cancer	Part(s) of the body affected
1	Carcinomas	The most common type of cancer. The cells originate from cells lining external parts of the body (such as skin) or internal linings of organs within the body (such as the oesophagus). Carcinomas usually affect organs or glands capable of secretion.	Breast, lungs, bladder, colon, prostate, pancreas, uterus, oesophagus, stomach, bowel, and others.
2	Sarcomas	These cancers originate in connective and supportive tissues.	Bone, fat, muscle and cartilage.
3	Leukaemia's	These refer to cancers in the blood. They affect bone marrow which is the site for blood cell production. When infected the marrow produces excessive white blood cells that cannot perform their usual role and so the patient is more susceptible to infection.	Blood.
4	Lymphomas	These arise from cells known as "lymphocytes" which are found throughout the body, particularly in the lymph glands and blood.	Hodgkin's disease and non-Hodgkin's disease.
5	Myeloma	This is a malignancy of the "plasma cells" in the bone marrow that produce antibodies - the proteins that help fight infection.	Bone marrow
6	Melanoma	Skin pigment-producing cells or "melanocytes".	Skin

Table adapted from Rees (2004, p.6)

Cancers are hereditary and may also develop based on things in the environment such as UV rays, or factors relating to lifestyle such as smoking, having a high Body Mass Index (BMI) and not by not engaging in enough physical activity (WHO, 2015). Breast and prostate cancer account for over half of newly diagnosed patients in the UK each year (CRUK, 2015a). Current UK projections about cancer incidence rates from now until 2035 estimate that more men will be diagnosed with cancer compared to women (48.42% compared to 36.41%); men will be most commonly diagnosed with prostate cancer and women with breast cancer; followed by bowel cancer and lung cancer for both sexes (Smittenaar *et al.* 2016).

Cancer is commonly detected by patients themselves, after they have identified a suspicious symptom and presented it to their local physician. One or more of the following symptoms that has lasted for more than two weeks may be a cause for concern: a change in bowel or bladder habits, unusual bleeding or discharge, a persistent cough or hoarseness, an obvious change in the appearance of a wart or a mole, as well as more (Nicholson-Perry & Burgess, 2002; CRUK, 2015c). Cancer may also be detected by a screening programme, or by chance while a patient is undergoing a procedure for a different medical problem. After a physical examination, a patient will undergo a series of diagnostic tests to confirm or disconfirm the suspected disease. These include: blood tests; modern cross-sectional imaging such as x rays, Computed Tomography (CT) or Magnetic Resonance Imagery (MRI); and a biopsy of the infected tissue site (CRUK, 2015b). Once a suspected cancer is confirmed, the tumour will be “staged” and “graded” to determine the extent of the disease, the patient’s likely prognosis and appropriate treatment (James 2011, p. 51-2). The “grade” refers to the microscopic appearance of the cells and predicts how quickly the tumour is likely to grow and spread. Cancers are graded on a continuum from low, “well differentiated” cells (cells that are close to normal cells and tissues and likely to grow at a slow pace), to high, “undifferentiated” cells (cells that are more aggressive and which display little or no resemblance to their tissue of origin). The “stage” of the cancer refers to the size of the tumour and whether it has spread to other parts of the body such as the lymph nodes or another organ. Different types of staging systems are used for

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different types of cancer, although the following stages commonly apply to most cancers (CRUK, 2014b; NHS Choices, 2015):

1. **Stage 1** - the cancer is relatively small and contained within the organ it started in.
2. **Stage 2** - the cancer has not started to spread into surrounding tissue but the tumour is larger than in stage 1.
3. **Stage 3** - the cancer is larger and may have started to spread into surrounding tissues and/or lymph nodes in the area.
4. **Stage 4** - the cancer has spread from where it started to at least one other body organ; also known as "secondary" or "metastatic" cancer.

Cancers with a low grade and low stage have a better chance of being treated successfully (McReady & MacDonald, 2006; NHS Choices, 2015; CRUK, 2014a; Tobias & Hochhauser, 2015).

A patient is usually prescribed a course of invasive treatments to try and destroy the tumour and cure the cancer. The main types of active treatment include surgery, radiotherapy and multiple types of cancer drugs including hormone therapy, chemotherapy, transplants, biological therapies and bisphosphonates (Nicholson-Perry & Burgess, 2002; Palmieri, Bird & Simock, 2013; CRUK, 2015b). It is commonplace for patients to receive multiple treatments to remove the tumour. With breast cancer, for example, a patient may first have surgery to remove the tumour followed by a course of chemotherapy to remove any remaining cancerous cells left in the surrounding tissue. This may be given in reverse order if the tumour is large to preserve more of the breast (and to prevent the patient from having a full mastectomy) (NHS Choices, 2014). All patients receive palliative treatment in addition to curative treatments which focusses on alleviating the pain and symptom burden associated with treatment side effects and the patient's emotional well-being. Doctors may prescribe palliative treatment only if the patient is too unwell to receive active treatment (i.e. if the cancer is too advanced at the diagnosis stage or if the patient has existing comorbidities that will make it harder to recover from invasive treatments); or if the cancer is continuing to grow despite multiple attempts at curing the disease. A treatment plan will be determined by a team of medical professionals in multidisciplinary team

meetings and discussed with the patient and their significant others in subsequent consultations (Palmieri, Bird & Simock, 2013; Tobias & Hochhauser, 2015).

Cancer is a leading cause of morbidity and mortality worldwide. In 2012, there were 14 million new cases of cancer and 8.2 million cancer-related deaths, figures that are expected to rise by 70% over the next two decades (WHO, 2015). There are approximately 2.5 million people who have had a diagnosis of cancer currently living in the UK and, similar to global incidence rates, this number is set to increase, with current statistics estimating a 3 per cent rise per year (Maddams *et al.*, 2009; Maddams, Utley & Møller, 2012). To put this increase into perspective further, by the end of 2016 more than 1,000 new patients will be diagnosed with cancer each day in the UK (Macmillan Cancer Support, 2015b), and by 2030 there will be over 4 million people living with and beyond a diagnosis, including newly-diagnosed patients, patients in treatment and cancer survivors (Maddams, Utley & Møller, 2012).

1.3 The Supportive Care Needs of those Affected by Cancer

Cancer is a widespread and feared disease that can have a devastating impact upon a patient's physical and emotional well-being, as well as causing distress for the significant others involved in their care. Those affected by cancer must navigate through distressing circumstances such as hearing the bad news of a diagnosis, managing the often debilitating side effects associated with cancer treatments, living with uncertainties such as whether the disease will spread or return in the future, as well coping with end of life and bereavement (Wilkinson & Kitzinger, 2000; Pitceathly & Maguire, 2003; Holland *et al.*, 2010; Caughlin *et al.*, 2011; Clinton-McHarg *et al.*, 2014; Miller, 2014). Those affected by cancer report a range of informational, practical, medical and psychosocial needs which, if addressed, can help them cope better with the burdens associated with the diagnosis (Eriksson & Lauri, 2000; Janda *et al.*, 2008; Sklenarova *et al.*, 2015). A literature review about supportive care needs by Shelby *et al.* (2002) found that 60 – 90% of patients and caregivers reported a need for assistance in at least one area over the course of the illness, but 18 – 30% reported that one or more of their needs always remained unmet.

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Many cancer patients and their families turn to various sources of information to feel better informed about the disease and what might happen in the future. A systematic review by Finney-Rutten *et al.* (2005) found that cancer patients commonly reported a need for information about three main things: 1) information about their specific cancer type including physical symptoms that may arise from their diagnosis and how cancers are staged; 2) information about treatment including treatment side effects, treatment options and treatment plans; and 3) information about their prognosis including their chance of cure after treatment, their estimated life span and the likelihood of cancer recurrence. People involved in the care of cancer patients such as partners and family members reported similar needs including information about treatment, diagnosis and prognostic matters (Janda *et al.*, 2008; Adams, Boulton & Watson, 2009; McCarthy, 2011). While most people affected by cancer reported that information helped them cope with the psychological impact of cancer, Adams, Boulton and Watson (2009) found that significant others were more likely to want psychosocial support about how to deal with their own emotions and how to cope with living with uncertainty about the future. Both patients and their carers were more likely to search for particular types of information at different stages of the illness with many reporting a need for information about cancer types and treatment during diagnosis and treatment phases; and information about long-term side effects, follow-up and self-management after treatment finished (Rees & Bath, 2000; Finney-Rutten *et al.*, 2005; Adams, Boulton & Watson, 2009; McCarthy, 2011).

However, despite these preferences for information and psychosocial support, many people affected by cancer report high levels of unmet supportive care needs. According to Lambert *et al.* (2012, p. 224): “a need is typically labelled as ‘unmet’ when services required to deal with the particular issue are not received”. A systematic review by Harrison *et al.* (2009) found that cancer patients reported high levels of psychological, physical and informational unmet needs and these findings were corroborated in a later study by Clinton-McHarg *et al.* (2014) (see also Sanson-Fisher *et al.*, 2000). Psychosocial concerns about the cancer spreading or returning were reported the most during treatment and post-treatment phases; and information about side-effects and symptoms were needs that were rarely met at all stages of the illness (Harrison *et al.* 2009, p. 1125). People with advanced cancer or a poor

health status were more likely to report unmet needs compared to people with a supportive network (ibid). In terms of significant others, Lambert *et al.* (2012) found that partners and carers had a range of unmet supportive needs relating to emotional and psychosocial needs (emotional distress, wanting someone to talk to and how to provide emotional support to the patient); information needs (about what to expect in the future, prognosis, treatment, and death and dying); and a need for comprehensive cancer care (having access to healthcare services, a relationship with healthcare professionals and being informed about the services medical professionals can offer) (ibid; see also Eriksson & Lauri, 2000; Stenberg *et al.*, 2010; Turner *et al.*, 2013 Sklenarova *et al.*, 2015).

1.4 Government Initiatives to Support People Affected by Cancer

The Department of Health recognises that cancer patients and their families have immediate *and* long-term supportive care needs that need to be addressed in order for people to return to as normal a life as possible following a diagnosis of cancer and treatment (DoH, 2010; 2011). ‘High quality’ information and communication are recognised as integral components to the delivery of cancer care as they can reduce anxiety, improve quality of life, encourage patients to self-manage their own conditions and increase overall satisfaction with the services received (DoH, 2000; 2004a; 2010; 2011). This includes both written and verbal forms of information, advice and emotional support. In terms of written information, the reform strategy (DoH, 2011) states:

“Accurate, tailored, timely and accessible information is vital to providing a good patient and carer experience” (ibid, p. 18);

And in terms of verbal communication:

“Written information is an adjunct, not a substitute, for high quality verbal communication. The way healthcare professionals communicate with those using the health service profoundly affects the experience of care for patients. Good communication can facilitate early diagnosis, improve self-management, reduce emergency admissions, reduce

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inequalities in access and provision of care, and support people to return to as normal a life as possible following cancer treatment” (ibid, p. 47).

The Calman-Hine report (DoH, 1995), a landmark document that first put cancer on the UK policy agenda, welcomed opportunities for the National Health System (henceforth NHS) to work with other agencies so a high standard of cancer care could be delivered across the UK. A “big society approach” is advocated to tackle the social and economic burdens associated with cancer in more recent policy documents, one that includes collaborations between the state, cancer charities, telephone services, academic institutions, biomedical companies and patients themselves (DoH, 2011). Care provided by telephone services such as cancer helplines are particularly valued in the current health policy landscape because they are a means of providing high quality information and support to those affected by cancer at home (it is acknowledged that most problems associated with cancer and its treatment arise outside of hospital environments); and for a relatively low cost (a matter becoming more important in an increasingly rationed NHS environment). Helplines are also listed as one of the three “lifesavers” in the National Cancer Survivorship Initiative (DoH, 2010).

In 2009 the Ministry of Justice commissioned a report into the use of government-run helplines, highlighting the lack of knowledge of helplines from a national perspective (MoJ, 2009). In the remaining sections I will describe what we do know about cancer helplines focussing on three predominant research areas within the cancer helpline literature: 1) the reasons people turn to cancer helplines for information and support; 2) caller demographics and reasons for calling; and 3) caller and call-handler experiences of using cancer helplines.

1.5 Why do People turn to Cancer Helplines for Information and Support?

People affected by cancer overwhelmingly receive information from the healthcare professionals involved in the patient’s care (Leydon *et al.* 2000; Finney-Rutten *et al.*, 2005; James, *et al.* 2007; Carlsson 2009; Hardyman *et al.*,

2009), but there is growing evidence to suggest that people are turning to other sources to fulfil their supportive care needs such as informal support networks (e.g. family, friends and support groups), organisations (e.g. telephone helplines and charities), the media (e.g. radio and television) and the internet (Rees & Bath, 2000; Finney-Rutten *et al.*, 2005; McCarthy *et al.*, 2011; Foster *et al.*, 2015). In terms of what accounts for these trends, a qualitative study by Leydon *et al.* (2000) found that cancer patients placed faith in the information obtained from their doctors and therefore perceive little need to obtain information from additional sources. Furthermore, not searching for information allowed cancer patients to maintain a sense of hope for the future as it reduced the likelihood of finding negative aspects about what could happen over the course of their illness (*ibid.*). Carlsson (2009) similarly investigated the reasons people do not seek further information and found that many people avoided the internet because they did not perceive the information as credible. On the other hand, more people are turning to these alternative sources because their supportive care needs are not being met by their medical team. Problems communicating with medical staff is a key reason people affected by cancer are searching for help outside the health system. These problems relate to: not receiving enough information; receiving information that is contradictory inadequate or hard to understand; and not receiving enough support throughout the illness (especially when treatment ends) (Heinrich, Schag & Ganz, 1984; Rees & Bath, 2000; Tamburini, Gangeri & Brunelli, 2000; Shelby *et al.*, 2002; Chapman *et al.*, 2003; Celega *et al.*, 2008; Foster, *et al.*, 2015). A qualitative study by Foster *et al.* (2015) found that family members expressed concerns about asking questions during consultations or revealing their own emotional distress in case they distracted the discussion from the needs of the patient. These concerns fuelled their search for information and psychosocial support elsewhere (*ibid.*).

Cancer helplines are thus an alternative and important medium for those affected by cancer to obtain the supportive care they need throughout the illness, care which many perceive they cannot obtain elsewhere (Jefford & Tattersall, 2002; Shelby *et al.*, 2002; Tritter & Calnan, 2002; Foster *et al.*, 2015).

1.6 Caller Demographics and Reasons for Calling

A key objective of cancer helpline research within the past twenty years has been to understand who is using these services and for what reasons. These evaluations are important in terms of understanding the supportive care needs of cancer helpline users, to ensure the helpline has the resources to meet those needs, and to ensure the service is reaching out to their target population. This interest has been investigated on cancer helplines globally, from the UK (Slevin *et al.*, 1988; Boudioni *et al.*, 1999; Dean & Scanlon, 2007; Ledwick, 2012); to Europe (Lechner & De Vries, 1996; Reubseat *et al.*, 2006), Iran (Montazeri *et al.*, 1999); the United States (Altman 1985; Rainey, 1985; Anderson *et al.*, 1992; Marcus *et al.*, 2002; Squiers *et al.*, 2005; La Porta, 2005; Finney-Rutten, Squiers & Treiman, 2006); and Australia (Jefford *et al.*, 2005a; Jefford *et al.*, 2005b; Chambers *et al.*, 2011).

The methodology employed within these studies has predominantly been quantitative with many using “call-enquiry” forms to ascertain caller demographics and postal questionnaires to investigate the types of assistance sought by callers. The call enquiry form is a tool routinely deployed by helplines to understand who is using their service. Call operators ask callers a series of questions during the calls about their gender, age, ethnicity, education level, cancer type and sometimes (but not always) current treatment; and this information is then stored on a computer database. A sample of these records are then used for research purposes.

Findings from this research have shown that the profile of cancer users has remained consistent over time: women are more likely to use helplines compared to men (all studies); callers tend to be of a white ethnic origin (all studies); older people use helplines more often than younger generations (50 to 59 years, and 60 older)¹ (Rainey, 1985; Boudioni *et al.*, 1999; Jefford *et al.*, 2005a; La Porta *et al.*, 2005; Squiers *et al.*, 2005; Reubseat *et al.*, 2006; Dean & Scanlon, 2007); enquiries mainly relate to issues about breast cancer (all studies); and people personally affected by the illness use them more than

¹ It is hard to be clear on the exact age group because the studies have all used different groups to categorise age range. For example, some have used “below 30”, “30-49”, “50-59” and 60+; and others have used “30-39”, “49 or less”, “41-50”, or they have calculated the mean age and not provided a range.

members of the general public or other healthcare professionals (Rainey, 1985; Slevin *et al.*, 1988; Lechner & De Vries, 1996; Boudioni *et al.*, 1999; Montazeri *et al.*, 1999; Marcus *et al.*, 2002; Jefford *et al.*, 2005b; La Porta *et al.*, 2005; Squiers *et al.*, 2005; Finney-Rutten, Squiers & Treiman, 2006; Reubsear *et al.*, 2006; Dean & Scanlon, 2007; Chambers *et al.*, 2011). There are only a small number of studies that have considered the patients' stage of illness as an important factor for understanding why people were seeking assistance at that particular point in their diagnosis (Slevin *et al.*, 1988; Squiers *et al.*, 2005; Chambers *et al.*, 2011).

Findings about the reasons people telephone cancer helplines differs between each study and this primarily relates to: a) the mission statement of the helpline under investigation (i.e. whether it provides general information or if it specialises in a particular area such as psychosocial support); and 2) the categories within the "call enquiry forms" for recording this information (different helplines have different ways of coding caller requests). Slevin *et al.* (1988), for example, examined calls to CancerBACUP and found that callers requested "medical information" most frequently which included information about the patients' cancer type, treatment and likely side effects, prognostic information and information about cancer metastasis. The second most common enquiries were for "supportive information" which included people who asked about support groups, rehabilitation, terminal care, symptom control and those who requested emotional support. The third main reason for calling was for "preventative information" which, as the name suggests, was about how to minimise the likelihood of getting cancer and other associated risk factors (*ibid*). Although there is variation within what is included under the subheading "medical information" other studies have found that this is the most common form of assistance sought from cancer helplines: publication requests and cancer site information (Anderson *et al.*, 1992); more information about breast diseases (Montazeri *et al.*, 1999); information about the medical site (Marcus *et al.*, 2002); information about cancer diagnoses (Jefford *et al.*, 2005b); information about clinical trials (La Porta *et al.*, 2005); specific treatment information (Squiers *et al.*, 2005; Finney-Rutten, Squiers & Treiman, 2006). Other studies reported that most callers telephoned for information but they did not specify what the request was about: "medical information"

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(Lechner & De Vries, 1996), “calling for information” (Dean & Scanlon, 2007) and “had a question in mind” (Ledwick, 2012).

These findings suggest that those affected by cancer predominately turn to cancer helplines to obtain medical information – a supportive care need reported by many cancer patients and their families (see section 1.2). However, there are some methodological problems associated with the way these data were collected and coded. In much of the research conducted so far there is an assumption that callers telephone cancer helplines with one overarching concern which is frequently depicted as the callers’ “main reason” for calling. There has not been an investigation about other parts of the calls including whether callers volunteered more than one concern, what those concerns were and if there was a pattern to their placement within the interaction. There is an allusion to this matter in a couple of the existing studies. Rainey (1985), for example, working on a psychosocial helpline, states:

“It is very common...to have callers begin with the relatively “safe” gambit: ‘please give me information on cancer support groups in my area’. In many cases this will be followed by elaboration of other psychosocial concerns” (1985, p. 312).

The author thus recognises that callers may telephone the helpline to discuss a range of problems and order sensitive topics so they arise later on in the call. This finding was corroborated by Marcus *et al.* (2002) who found that psychosocial concerns about cancer recurrence and palliative care were present in 67% of their calls but they were often raised as “latent” (i.e. delayed) topics. The depiction that callers have a ‘main’ reason for calling is related to the reliance on “call enquiry forms” within the current research, forms that are designed by helpline organisations and which are rarely adapted for research use.

Chambers *et al.* (2011, p. 214) argue that future research needs to be conducted using a more “fine-grained approach” to understand the reasons people use cancer helplines more comprehensively. Based on the studies described so far, this could involve modifying the call enquiry forms to include the callers’ stage of illness, if multiple problems were volunteered and the

support provided by call-handlers because there is a current lack of knowledge about all of these areas. A qualitative study by Ekberg *et al.* (2014) - the only existing study that has examined helplines using a fine-grained approach - found that caller requests for “information” or “advice” were closely intertwined with requests for psychosocial support. This means that research using these ‘call enquiry forms’ may not have captured the callers’ reason for calling in enough detail (if at all).

1.7 Caller Experiences of Seeking Assistance over the Phone

Caller’ experiences of using cancer helplines have largely been investigated quantitatively too, with a key objective to measure caller satisfaction and the factors that best predict this. Linked to caller satisfaction is what some studies have referred to as the callers’ ‘emotional impact’ towards the call which measures the callers’ emotions (e.g. their anxiety or fears) before and after using the helpline and the degree to which the service met their expectations.

Overwhelmingly, callers reported high levels of overall satisfaction with the services received (Slevin *et al.*, 1988; Altman, 1992; Venn *et al.*, 1996; Darrow *et al.*, 1998; Lindgren & Boman, 2003; Reubsaet, Lechner & De Vries, 2006), with this sometimes exceeding 93% (La Porta *et al.*, 2005; Lechner & De Vries, 1996; Montazeri *et al.*, 1999; Dean & Scanlon, 2007; Dean & Ahmed, 2011). This satisfaction was based on the quality of information obtained (Altman, 1992; Darrow *et al.*, 1998; Reubsaet, Lechner & De Vries, 2006), with many reporting that their question was ‘fully’ or ‘completely answered’ (Venn *et al.*, 1996); that the information was ‘relevant’ to their situation (Lechner & De Vries, 1996; Dean & Scanlon, 2007; Dean & Ahmed, 2011); and ‘easy’ to understand (Montazeri *et al.*, 1999). Satisfaction was also influenced by the communication skills of the call-handlers with callers reporting that they were satisfied because the call-handler: was ‘easy’ to talk to (Slevin *et al.*, 1988); listened ‘properly’ (Venn *et al.*, 1996); provided a ‘good’ level of ‘attention’ and ‘respect’ (Lechner & De Vries, 1996; Reubsaet, Lechner & De Vries, 2006); was ‘knowledgeable’ and ‘trustworthy’ (Darrow *et al.*, 1998; La Porta *et al.*, 2005); ‘competent’ (Lindgren & Boman, 2003); ‘understood’ the caller’s needs (Dean & Scanlon, 2007); and ‘empathic’ (Dean & Ahmed, 2011). These two aspects, the

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quality of information obtained and the communication skills of the call-handlers, were found to predict caller satisfaction between all client groups (both those affected by the illness and members of the general public). A small minority of callers reported that were dissatisfied with the service(s) received (Dean & Scanlon, 2007; Dean & Ahmed, 2011; Lechner & De Vries, 1996; Lindgren & Boman, 2003; Reubsæet, Lechner & De Vries, 2006). Two of these studies allowed participants to write comments about their varying satisfaction and callers reported they were discontent because the helpline worker had been too intent on providing emotional support when the caller's query was about accessing medical information (Dean & Ahmed 2011, p. 27); and in another study callers said they were dissatisfied because they wanted the helpline to be more accessible (i.e. available at more times during the day) and to provide more information about their specific cancer type and treatment (Lindgren & Boman, 2003).

In terms of the 'emotional impact', most callers reported that they felt better after telephoning the helpline: in one study the majority of callers reported a decrease of anxiety and fear by 42% (Lechner & De Vries, 1996); and in another study 86% of callers reported that they felt "much more" or a "little more" cheerful after the call (Montazeri *et al.*, 1999). A small minority of callers in one study (4%) reported that their tension had increased since calling the helpline but the questionnaire did not provide space for them to explain why (Lechner & De Vries, 1996). Callers also stated that their expectations had been largely or completely met (Lechner & De Vries, 1996; Venn *et al.*, 1996; Reubsæet, Lechner & De Vries, 2006). The information obtained and the call-handlers' communication skills were again the best predictors of emotional impact.

The findings from these quantitative evaluations have confirmed that information and communication play a significant role in the delivery of telephone help for those affected by cancer, a view that is recognised in current health policy documents (DoH, 2000; 2004a; 2010; 2011). However, there are methodological problems associated relying on questionnaires to measure caller satisfaction. The studies applied their own constructs about what led to positive call outcomes such as: "did the nurse listen to you properly?", "was the information adequate?", "was the call-handler empathic?";

and callers rated these items on a Likert type scale. These measurements raise empirical questions such as: *how* was the information delivered that made the caller perceive it as “adequate”? How did the call-handler *display* empathy? And, perhaps more importantly based on the studies that found some callers were dissatisfied with the services received, what led to these displays and what consequences did they have upon the subsequent interaction? Such questions can only be answered by exploring the interactional behaviour of the participants *during* the calls.

There is a small evidence base that has examined caller experiences of using cancer helplines using qualitative methods. A recent interview study by Ekberg *et al.* (2014) found that cancer patients valued these services because: they are convenient to use, patients can speak with someone outside their social network so not to burden friends and relatives with their troubles, and they were perceived as a more reliable source of information compared to the internet. A minority of callers reported negative aspects of their call experience which they related to the communication skills of the call-handlers: one participant reported that the call-handler was ‘too formal’ and another reported that the nurse was not empathic towards their personal situation (*ibid*).

1.8 Call-handler Experiences of Providing Help over the Phone

There has been less research about the experience of delivering telephone-based support from the perspective of the call-handlers who staff them. An interview study with 30 call-handlers from three cancer helplines by Leydon *et al.* (in preparation) found that call-handlers were generally positive about their work and valued being able to spend dedicated time talking to callers and providing services that many acknowledged callers could not obtain elsewhere. However, they also described numerous challenges associated with their role. These included: managing caller expectations about what they are able to provide, knowing how deal with ‘difficult’ callers (i.e. ones who are distressed or angry), keeping up-to-date with the knowledge required to perform their role effectively, and gauging the relevant success of the call before the call ended (i.e. whether the caller was able to better manage their problems after speaking with a nurse) (*ibid*). Some call-handlers also discussed the fuzzy

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boundary between providing 'information', 'advice' and 'support' and many disagreed about whether advice-giving was within the remit of their role. Although this is the only study that has documented the views of cancer helpline workers specifically, there is evidence that these challenges are encountered by other nurses who deliver medical information and support over the telephone (Holmström & Dall'Alba, 2002; Holmström & Höglund, 2007; Farquharson *et al.*, 2012).

In summary, information and communication are recognised as integral components to the delivery of telephone-based cancer care which is supported by findings about what callers' value about these services and what call-handlers believe are important aspects of their job. However, thus far this view has been obtained by using retrospective reports of what callers and call-handlers think about cancer helplines rather than what happens during the calls. I pointed to the need for examining helplines using a more "fine-grained analysis" (Chambers *et al.*, 2011) to study aspects of helpline communication in more detail such as: why callers turn to cancer helplines, the types of enquiries volunteered throughout the call rather than just at the beginning, how nurses deliver different aspects of this care and how the problems associated with helpline work are managed during the calls (or not). In the next section I will focus on research that has applied a fine-grained analysis to the study of helpline communication and argue that using such an approach will fill an important evidence gap in the current cancer helpline literature.

1.9 Conversation Analytic Examinations of Helpline Talk

Conversation Analysis (henceforth CA) is a qualitative micro-analytic method that is used to investigate social interaction in various situations of everyday life (Atkinson & Heritage, 1984). Audio and video recordings of "naturally occurring" conversations are transcribed in detail and subjected to repeated examination to provide a systematic account of the communicative practices people use when interacting with each other (Sidnell & Stivers, 2014). The use of naturally occurring talk means that the interaction would have taken place regardless of the research interest which removes problems associated with using retrospective accounts of human behaviour. The objective of CA is to understand how meaningful social actions (e.g. requests, advice, offers, complaints) are produced and interpreted by participants to the interaction,

and the consequences these have upon the unfolding organisation of the talk (Drew, Chatwin & Collins, 2000; Schegloff, 2007).

CA has intellectual roots in understanding how institutional help is sought and provided over the telephone which has grown steadily over the years. This began with pioneering work by Sacks (1967; 1992a; 1992b) on calls to a Suicide Prevention helpline. One of his most influential analyses was about the opening moments of the calls when callers formulated their 'reason(s) for calling'. He found that many callers accounted for their call by claiming that they had "no-one to turn to". Sacks (1967) argued that this device served a dual function for: a) justifying the callers' rationale for wanting to commit suicide and b) telephoning a helpline for professional assistance because in claiming that they had *nobody* else to talk to the callers emphasised their inability to self-manage or resolve their troubles on their own (Sacks, 1967; 1992a; 1992b). Since Sacks, a number of studies have sought to describe how various kinds of institutional help are provided over the telephone, including work on the emergency services, where the conduct of both participants reflects the urgency in dispatching emergency assistance (such as the police, fire brigade or ambulance) (Wakin and Zimmerman, 1999; Whalen & Zimmerman, 1987; Whalen & Zimmerman, 1990; Zimmerman, 1992); and work on a range of helplines, where the "help" provided is in the form of talking through the callers' problem(s) with an aim to provide callers with the resources to better manage their problem(s) on their own after the call (Potter & Hepburn, 2003; Baker, Emmison & Firth, 2005; Shaw & Kitzinger, 2005; Drew, 2006; Emmison & Danby, 2007; Shaw, 2007; Edwards & Stokoe, 2007; Butler *et al.* 2009; Hepburn & Potter, 2011; Shaw & Kitzinger, 2013).

In the following paragraphs I will outline the potential of CA for understanding helpline communication by describing three studies that have conducted fine-grained analyses in this area. The examples will highlight how CA work can be used to understand why people use helplines and how the organisation operates, as well as how findings from conversation-analytic research can be used to change aspects of service delivery (Hepburn, Wilkinson & Butler, 2014).

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1.9.1 Calls to a Home Birth Helpline

The home birth helpline is a British telephone service that seeks to empower women in enacting their decision to arrange a home birth (Shaw & Kitzinger, 2013). Women, at least in the UK, America and parts of Europe, have the legal right to choose where they want their child's birth to take place regardless of the woman's age, whether it is her first birth or any other perceived risks that could occur during labour. Medical professionals, however, often dissuade women from choosing a home birth and encourage hospitalised births by using the rhetoric that the 'needs', 'safety' and 'well-being' of the mother and child will be better ensured if they are in this setting (Shaw & Kitzinger 2007b, p. 204). The Department of Health (DoH, 1993; 2004b) recognises the importance of providing women with sufficient information and support so they are able to plan their own care but, for the reasons described above, this rarely occurs in reality due to the privileged status of hospitalised birth in Western societies (Shaw, 2007; Shaw & Kitzinger, 2005). The birth helpline is thus an important service where women can obtain the supportive care they need to arrange a home birth without having to justify their desire for doing so (as they might have to with doctors and peers in their supportive network) (Shaw, 2006).

A sample of eighty calls were collected by Shaw (2006) for her doctoral research which included interactions between fifty-six callers and one call-handler. Forty-eight callers were using the helpline for the first time and the remaining callers were using the service for a second or third time. A thematic analysis was first conducted to understand the problems brought to the helpline and four main reasons for calling were identified: help arranging a home birth (45%), repeat calls about the ongoing planning of a home birth (21%), calls for general information (19%) and birth reports (15%) (Shaw & Kitzinger, 2005). The authors further explored these findings with a qualitative analysis about how callers formulated their 'reason for calling' in the opening phase of the call. They found that callers frequently described a dilemma which included: 1) a want (or plan) to have a home birth and 2) impediments to that desire being granted. For example: [*right well basically I really would like a home birth*] + [*but my GP isn't that keen*] (simplified transcript) (Shaw & Kitzinger, 2007b, p. 207). Similar to the work by Sacks (1967; 1992a; 1992b), this accounting work justified the callers' reason for calling because they were

unable to arrange a home birth through their immediate medical team but still required knowledge about how to organise one.

Another interest about this helpline was how the helpline's philosophy of empowering women to plan a home birth was enacted through the call-handler's practices for providing information and advice during the calls. Shaw and Kitzinger (2005) found that this was primarily achieved with positive assessments such as: "*you're brilliant, I admire what you're doing, I think you got it balanced beautifully right*", and so on. The authors (ibid) argued that these assessments were in-keeping with the helpline's philosophy to empower women as they were often directed at the callers' personality, achievements and actions. The utterances differed to the compliments studied by Pomerantz (1978) and were instead ways of enacting (i.e. *doing*) supportive actions. Evidence for this claim was based on the way some callers responded to these assessments, not by avoiding self-praise or accepting the compliment, but by raising possible problems about what they planned to do. For example, one caller responded to the assessment *I think you're going about it the right way*, with, "*Do you think I've got enough time to sort it though*" (Shaw & Kitzinger 2012, p. 233). Aspects of empowerment were also evident in the strategies used to manage distressed callers (Shaw & Kitzinger, 2013).

This research provided a comprehensive understanding about the inner-workings of the Home Birth helpline and *how* the call-handlers' communicative conduct served to empower women to enact their right to organise a home birth. Some of the findings were used to train call-handlers about how to respond to distressed callers (Shaw & Kitzinger, 2013) and a leaflet about how to plan a home birth was also distributed to GP surgeries (Shaw & Kitzinger, 2007a).

1.9.2 Calls to the National Society for the Prevention of Cruelty to Children (NSPCC)

The NSPCC is national charity in the UK which aims to safeguard children from neglect, abuse and other forms of inappropriate behaviour. The helpline is legally mandated to pass on reports of abuse to social services or police where the information is sufficient and merits action, regardless of whether the caller

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wants to remain anonymous or not (Hepburn, 2005). The service also provides free counselling, information and advice to anyone concerned about a child at risk of ill treatment, or children themselves who may be at risk. The helpline is staffed by trained social workers called Child Protection Officers (henceforth CPOs) who have had at least three years of field experience working in child protection. The majority of calls (80%) do not involve referrals to social services for numerous reasons including: 1) there is no immediate risk to the child; 2) the child is already known to social services or medical personnel and they are already intervening; or 3) the report is from a relative of the child (e.g. separated parent, grandparent) who is making allegations in the context of an ongoing custody dispute. A large proportion of calls thus involve the delivery of information and advice (Potter & Hepburn 2003, pp. 200-201; Hepburn & Potter 2011, pp. 220-221).

Similar to Sacks (1967) and Shaw and Kitzinger (2007a), the first analysis about this helpline was about how callers formulated their reason for calling. Potter and Hepburn (2003) found that many callers used a 'concern construction' such as *I'm concerned about X* or *I'm a bit concerned*. The authors (ibid) note several features about this turn design: 1) they are hearably incomplete and thus project an extended narrative about violence or abuse towards a child; 2) they are designed appropriately for this institutional context as the caller displays uncertainty toward the object of their concern and whether it is actionable by the NSPCC; 3) they display an appropriate attitude or stance toward the putative abuse; and 4) they manage epistemic asymmetries between the callers' knowledge of the abuse and the CPOs knowledge about whether the problem is suitable for a child protection service (ibid).

The authors also worked on a collection of calls that involved callers who were emotionally distressed as this was described by CPOs as a challenging aspect of their work (Hepburn and Potter, 2010). This research extended the first author's work on crying (Hepburn, 2004) and crying receipts (Hepburn & Potter, 2007), and focussed on the call-handlers' use of tag questions when responding to emotional displays (Hepburn & Potter, 2010). They found (ibid) that tag questions contained a declarative and interrogative element such as [*it's very hard when they're not there with you*] + [*isn't it*] and [*well you're doing what you can now to actually offer them protection and help though*] +

[“*aren’t you*”]. Hepburn and Potter (2010) argued that the declarative component is empathic and provides reassurance about the callers’ actions while they are crying with an aim to refocus the caller back on the report of abuse. The interrogative component validates the callers’ epistemic position (their knowledge/perception about the situation) and encourages the caller to participate in the interaction at a point when it might be in doubt (i.e. it refocuses the interaction on the reported abuse and keeps the caller on the telephone line in case their claim needs to be forwarded to the police or social services) (ibid).

Finally, Hepburn and Potter (2011) examined the resources used by CPOs to manage callers that were resisting advice. The call-handlers used several interrelated practices to minimise this resistance including: 1) repackaging the advice into an idiomatic form as this made the advice hard to counter; 2) following the idiomatic form with a tag question to build/“design the recipient” as already agreeing with the stance taken by the CPO; and 3) talking past the transition relevance place of the tag question to dampen the requirement for the caller to participate at this point (thus projecting an expectation that no further resistance will occur) (ibid).

This research provided an in-depth understanding about the challenging aspects associated with working on a helpline that provides information and advice about various sensitive topics. Findings from these analyses led to communication training for call-handlers about how to respond to advice resistance and how to manage emotionally-charged callers (i.e. ones that are angry, distressed or upset) (Hepburn and Potter, 2010; 2011).

1.9.3 Calls to a Child Health Line

The Child Health Line is a 24-hour Australian telephone service that delivers information and support for parents and families on children’s health, behaviour and development; as well as information about parenting. A quantitative analysis of 300 calls revealed that callers predominantly telephoned the helpline for parenting advice (48%), followed by medical advice (22%) and 26% sought assistance about both medical and parental-related problems (Butler *et al.* 2009, p. 820). The service is staffed by trained nurses

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but they are legally mandated by helpline guidelines *not* to provide medical advice which impose multiple constraints and tensions upon the calls. Compounding these tensions are: 1) the lack of visual cues to interpret the boundaries between “health” and “illness”; and 2) the blurred lines between what constitutes “medical” and “nonmedical advice” (Butler *et al.* 2009, p. 819).

Butler *et al.* (2009) examined how the nurses managed the boundary between information and advice-giving during the calls. A request was defined as ‘medical’ if the callers were: “...seeking diagnostic assessment, advice about seeking medical attention and information about ostensibly medical conditions” (ibid, p. 820). Three predominant practices for responding to caller requests for medical advice were identified including: 1) using membership as a nurse to establish boundaries of expertise (e.g. “*I’m just a nurse*”); 2) privileging parental authority regarding decision making about seeking treatment (e.g. “*I have to say you should go and get her checked out but it’s your choice, it’s your decision on her signs and symptoms of what she is doing at the moment*”); and 3) drawing upon the nurses’ expertise in the domain of parenting and child development to offer information and advice that addressed the callers’ problem without providing medical advice (e.g. “*I mean we deal with breastfed babies all the time and...as child health nurses*”).

This research led to understandings about how nurses managed the practical dilemmas associated with following institutional mandates during the calls. The authors suggest that these findings could be used to train nurses in the future about how to reconcile the tensions associated with following organisational guidelines and meeting the callers’ expectations (Butler *et al.*, p. 832; Butler, Danby & Emmison, 2015).

In summary, CA work on helplines shows how, through various conversational practices, telephone-based services are “talked into being” (Heritage, 1984b). This was evident in the practices used by callers to request assistance as well as the practices used by call-handlers to deliver ‘service-appropriate’ information, advice and support. Findings from CA research can also be turned into recommendations for call-handling practice. CA is thus a valuable methodology in term of understanding the communicative process of seeking and delivering professional assistance on the telephone.

1.10 Aims of the Current Thesis

The aims of this research are to fill the evidence gap described in the current cancer helpline literature by conducting a conversation analytic examination of cancer helpline talk. The following research questions were used as a guide for possible areas of interest based on the themes described in the previous literature and were subsequently refined as inductive analyses commenced:

1. What problems are brought to cancer helplines and how are they sought?
2. What types of care do call-handlers provide and how are they delivered?
3. If communication difficulties associated with helpline work arise during the calls, what are they, and how are they managed by the participants?

In the final section of this introductory chapter I provide an overview of the main chapters within this thesis (readers who wish to move directly onto Chapter 2 should skip to page 27).

1.11 Chapter Outlines

This research, like all conversation-analytic work, is data-driven and inductive. The analytic foci of my forthcoming empirical chapters arose from repeatedly listening to the calls, transcription and in-depth analyses. The topics selected were thus formed from my observations about the participants' interactional behaviour during the calls and were not pre-determined before data analysis commenced. In **Chapter 2** I explain these methodological principles in more detail, as well as key information about participant recruitment, the sample of calls used for this research and finally how I managed relevant ethical issues.

In **Chapter 3** I introduce the helpline data and describe the phase-structure underpinning the calls, caller' 'reasons for calling' and multiple issues, and the frequent ways in which call-handlers responded to caller requests. This quantitative overview provides a comprehensive understanding about how people affected by cancer use this service as well as how this organisation operates. This coding work was useful in terms of understanding the data and for deciding upon the phases/problems to qualitatively investigate.

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In **Chapter 4** I begin by describing how callers presented their medically-related problems to a nurse. I compare how the structural design of these presentations compares to the resources people use to present their various problems to primary care physicians and helpline organisations. In the second part of the chapter I describe a frequent problem volunteered by callers as their 'reason for calling' about troubling symptoms the patient was experiencing. The examination of caller problem presentations will provide understandings about how medical problems arising from a cancer diagnosis were presented to helpline nurses; and caller' motivations for seeking assistance from a cancer helpline (rather than another medical professional).

In **Chapter 5** I examine another frequent caller request for assistance, this time about the patient's prognosis. This chapter will build upon findings from Chapters 3 and 4 as I examine how callers volunteered additional problems to the one they initially presented as their 'reason for calling'; and I also describe the resources used by call-handlers to respond to these requests. This chapter will lead to an understanding about how a notoriously difficult topic associated with cancer is discussed by participants on the telephone; and how the nurses managed a challenging aspect of helpline work (i.e. responding to enquiries that are outside the remit of their expertise).

In **Chapter 6** I examine how the calls were brought to a close and how within closing moves callers expressed their satisfaction or otherwise with the services received. Findings from this chapter will provide understandings about how helpline calls are brought to a close (existing research has focussed on doctor-patient interactions and calls to the emergency services); as well as how caller satisfaction can be measured endogenously rather than using self-reported data.

In the **final chapter** I will assess the thesis as a whole focussing on the contributions it makes to existing research about cancer helplines and medical communication; the limitations of using such a fine-grained approach; implications for practice; and I will also recommend areas for future research.

Chapter 2: Methodology

2.1 Introduction

In this chapter I will provide a detailed account of how the research was carried out. In the introductory chapter (p. 2) I explained that my research is part of a broader helpline study that aimed to map a current understanding of helplines in the UK. Two of the work streams involved qualitative research: 1) in-depth interviews with callers and call-handlers about their experience of using cancer helplines; and 2) an exploration of how telephone based cancer care is sought and provided over the telephone using conversation analysis (CA). In section one I will describe issues relating to *data collection* including: a description of the helpline, its mission statement and the types of support it aims to provide; participant identification and recruitment; a description of the data collected; and, more specifically, a description of the sample of calls worked with for this PhD research. Next I will describe the *methodological underpinnings* to this research including the principles and tenets of Conversation Analysis (CA) and how they informed my approach to data analysis. In the final section I will describe relevant *ethical issues* and how they were managed.

2.2 Data Collection

2.2.1 Study Site

Macmillan is a charity-funded organisation that provides information and support to those affected by cancer. The charity has a long history, dating back to 1911 when Douglas Macmillan first established the Society for the Prevention and Relief of Cancer. In order to understand the placement of the charity in society today, especially the helpline, a merger with another organisation called *CancerBACUP* needs first to be detailed. In 1985 Dr. Vicky Clement-Jones formed the organisation *CancerBACUP* (British Association of Cancer United Patients – and their families and friends), a national information service staffed by oncology nurses that provided people affected by cancer, the public and health care professionals with medical information about cancer. Dr Clement-Jones was diagnosed with ovarian cancer in 1982, a shock diagnosis that left her feeling hopeless and alone. Cancer posed emotional and practical problems which she did not foresee ranging from the embarrassment of severe

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hair loss during chemotherapy, to the hardship of transitioning from a cancer patient to a “normal” life. During this time, she found solace in the provision of information and support, both from her medical team and from other cancer patients. This information enabled her to make informed decisions about medical treatment and it also helped her cope with traumatic aspects of her illness. Her personal experience of cancer led to an understanding that those affected by cancer require *both* medical and experiential information, which she sought to provide through a national organisation (c.f. Clement-Jones 1985 for a full discussion about her cancer experience).

The Macmillan helpline first opened in 1997 and received over 11, 000 calls within its first year. It merged with *Cancerlink* in 2001 (another cancer information charity, with a particular focus on self-help and support groups) and *CancerBACUP* in 2008 (described above), a partnership which afforded Macmillan with their current status of the leading national cancer charity in the UK. The charity ensures it is visible within the public sphere and runs numerous media campaigns, including television and billboard advertisements, to promote the service to those affected by cancer, as well as encouraging people to donate. The mission statement of the helpline is to provide a source of information and support to those affected by cancer, and to ensure nobody faces cancer alone. The following excerpt, for example, highlights this, and comes from a page on the charity’s website:

“When you have cancer, you don’t just worry about what will happen to your body, you worry about what will happen to your life. At Macmillan, we know how a cancer diagnosis can affect everything and we’re here to support you through. From help with money worries and advice about work, to someone who’ll listen if you just want to talk, we’ll be there. We’ll help you make the choices you need to take back control, so you can start to feel like yourself again. No one should face cancer alone. We want to reach and improve the lives of every one of those people” (Macmillan Cancer Support, 2015a).

The helpline is free to call, and in dialling this number callers are able to obtain “support” on a range of medical, financial and emotional issues, as well as having access to the large amount of information on the helpline’s website.

“Support” comes in the form of verbal information, booklets and factsheets, advice, and (emotional and psychosocial) support (this will be explained in more detail in Chapter 3). Support can also be obtained from Macmillan’s online forum, a recent development that enables people to pose queries to cancer specialist nurses and other people affected by cancer online.

The helpline operates a triage system which means that all calls are put through to a frontline member of staff known as an Information Support Officer (or ISO for short) and they decide, based on the callers’ problem presentation, whether to handle the request, whether to triage the caller to a member of the welfare rights and benefits team, or to triage the caller to a cancer specialist nurse. This system is represented schematically in the following diagram:

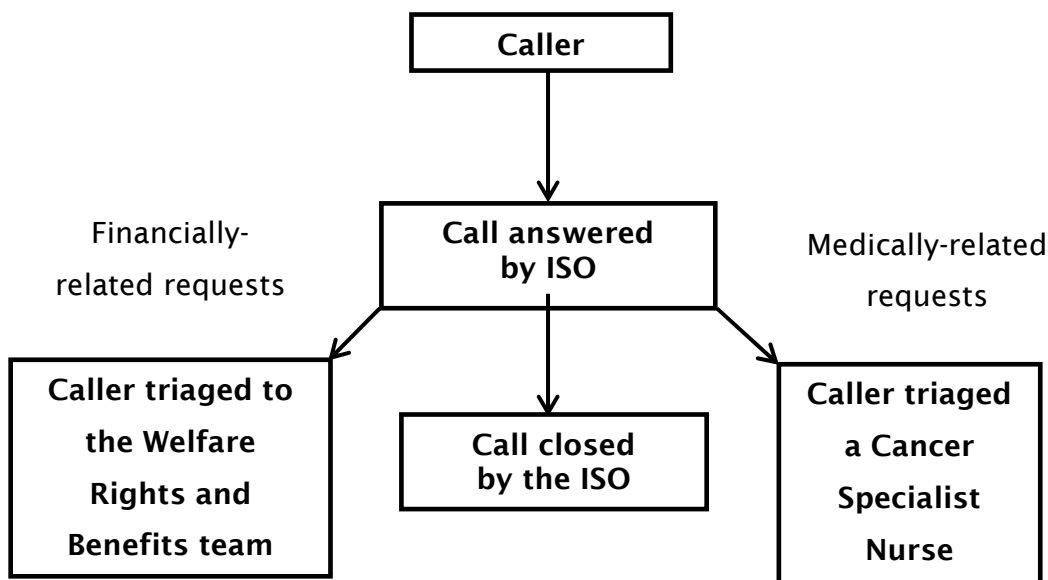


Figure 1: Representation of Macmillan's Triage System.

Callers with concerns about financial issues, such as being able to pay bills while taking time off work for treatment or being able to afford transportation to hospitals, are triaged to a member of the welfare rights and benefits team. These call-handlers mainly provide information about the caller’s entitlement to benefits or their eligibility for specific grants that will help them with the cost of living with cancer. The conversations involve a detailed discussion of the caller’s current financial situation (e.g. covering all income and expenditure). Callers that have medical enquiries relating to current treatment,

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treatment options, symptom management, health deterioration and so on, are triaged to a cancer specialist nurse. Nurses are able to provide medical information, emotional support and *some* forms of medical advice. Advice to speak with another healthcare professional or advice about how to reduce the symptom experience of treatment side effects are examples of what they are able to provide; but they cannot advise callers about what treatments to choose, deliver prognoses or diagnose symptoms². ISOs are not trained in and do not have the medical expertise associated with cancer specialist nurses, nor do they have the detailed knowledge about finance which is the reason callers are triaged to the other call-handlers. They are able to provide some levels of information/support, such as directing the caller to a useful part of Macmillan's website, providing the caller with a telephone number of a local support group or providing reassurance to a distressed caller; but callers requiring more specialist information are triaged to one of these two departments.

Macmillan cancer support was chosen to conduct the case study about helpline communication because it provided access to a range of people affected by cancer (friends and relatives, as well as cancer patients), a range of cancers (some helplines such as *Breast Cancer Care* and *Prostate Cancer UK* are cancer specific) and the range of supportive care needs associated with them. This particular helpline would therefore facilitate an understanding about how a variety of problems and difficulties arising from a diagnosis of cancer are discussed on the telephone.

2.2.2 Participant Recruitment

Call-handlers were first recruited by the study team in 2010. GL and KE³ presented the study aims and approach to potential call-handlers during a series of face to face meetings at Macmillan's head office to ensure all call-handlers had an opportunity to ask questions prior to deciding whether or not to take part. Call-handlers were informed about: 1) an in-depth interview study

² The remit of services within the role of MCS cancer specialist nurses is similar to the roles of the nurses described in the study by Butler *et al.* 2009 (see Chapter 1, p. 23).

³ GL stands for Dr. Geraldine Leydon (the chief investigator of the broader helpline study) and KE stands for a Dr. Katie Ekberg (a postdoctoral researcher who worked on the project for two years).

about their experience of using or working on the helpline and 2) a conversation-analytic examination of MCS calls. As access to the call recording could be perceived as threatening or an interference to call-handler practice, call-handlers had to have finished their probation period in order to be eligible to participate. In total, 39 call-handlers agreed to take part in the study, 21 ISOs and 18 cancer information nurses.

The recruited call-handlers screened callers for their eligibility to take part in the research during the calls. Macmillan routinely records their calls and ISOs routinely ask callers if they would be willing to take part in future research in a 'data collection' phase of the call (this will be explained in Chapter 3). Callers are asked if they can be contacted about future research opportunities by email or post which is then noted in their call record. Callers who agreed to have information sent by *post* were sent an information pack by the study team. The callers had to be over 18 years of age, able to offer informed consent, English-speaking and first time callers with a past, current or suspected cancer. ISOs do not screen callers who are overly distressed or acutely unwell to take part in future research. The first mail out of recruitment packs occurred between July 2010 to December 2010; and the second occurred between January to August 2011. After callers provided informed consent, the calls were given to the study team via a series of secure electronic transfers.

2.2.3 Data

The helpline project research team aimed to collect between 200-300 helpline calls and ultimately collected 326 in total. The reason for collecting this large number was to ensure a range of callers with different cancer types and concerns were included for analysis. A large amount of calls also ensured that patterns within the data were not based on one call-handlers idiosyncratic style of providing assistance but instead on the practices most call-handlers used to deliver this care over the telephone (see Drew, Chatwin & Collins, 2000).

A brief breakdown of the corpus is provided in the following table.

Table 2: Macmillan Helpline calls corpus description

Calls Recorded	Amount
ISO-only calls	
1) Callers' issue responded to and resolved by the ISO	94
2) Caller referred to the welfare rights team	96
3) Caller referred to a cancer specialist nurse	36
4) Caller referred to a cancer specialist nurse and the welfare rights team.	1
Total no. ISO-only calls	227
Matched nurse calls	
1) Caller triaged to a cancer specialist nurse and they responded and resolved the callers' issue(s)	99
Total no. of calls in the Macmillan helpline corpus	= 326

The vast majority of calls within the helpline corpus are “ISO-only” calls and they either involve the ISO handling the caller’s request and closing the call, or referring the caller to one of the other specialist departments. 99 of the calls are “matched⁴ nurse calls” and involve callers who were triaged through to a cancer specialist nurse. This call involves the interaction between the caller and the ISO, the ISO passing on the caller’s details to a nurse during triage, and the caller speaking with a nurse in the third part of the call. 9 of the calls are “nurse-only” calls which means the recording has the nurse-part of the call but not the caller’s conversation with the ISO. The majority of callers were immediately triaged to a nurse (no=74), but some had a nurse call-back arranged (no=22) and others (no=3) telephoned the helpline again and asked to be put through to a nurse. Callers may not be triaged straight away if the service is particularly busy at the time of the call.

My research is based on the 99 matched and nurse-only calls. I sampled the corpus in this way because:

⁴ They are labelled “matched” calls because both parts of the call – the ISO and nurse – involve the same caller, and so the call parts essentially “match”.

1. Most of the communication difficulties associated with talking about cancer occurred in the second part of the call as the callers were speaking to the nurses;
2. A large proportion of the ISO calls are incomplete and we only have the first part of the call as the ISO informs the caller that they need to be triaged to another department rather than how their request was subsequently handled. The sample of calls used for this research have a consistency in the type of problem presented (they all involve medical concerns) and the business of the encounter is discussed before the call is brought to a close;
3. Lastly, it would be unfeasible for a PhD thesis to analyse such a large number of calls in the entire Macmillan corpus within three years. The sampling decision is thus also – if not mainly – related to a pragmatic decision to demarcate a manageable corpus to work with.

2.2.4 The Participants

The 99 calls used for this research involve interactions between a range of people affected by cancer and a range of call-handlers (16 ISOs and 18 nurses). The following table provides a breakdown of caller demographics. The nature of the callers' problem(s), whether they raised multiple concerns and the support provided by the call-handlers will be described in detail in Chapter 3.

Table 3: Breakdown of caller demographics.

	Patients		Carers		Total	
	Number	Percent	Number	Percent	Number	Percent
Caller status	53	53.5%	46	46.5%	99	100
Gender						
Male	15	28.3%	7	15.2%	22	22.2%
Female	38	71.7%	39	84.8%	77	77.8%
Ethnicity						
White	9	17.0%	13	28.3%	22	22.2%
White, British	26	49.1%	21	45.7%	47	47.5%
White, Irish	1	1.9%	1	2.2%	2	2.0%
White, other	3	5.7%	0		3	3.03%
Asian, British	1	1.9%	0		1	1.01%
Dual heritage	2	3.8%	1	2.2%	3	3.03%
Not asked	6	11.3%	7	15.2%	13	13.1%
ISO-only calls	5	9.4%	3	6.5%	8	8.1%
Cancer type						
Bowel	2	3.8%	3	6.5%	5	5.1%
Breast	16	30.2%	7	15.2%	23	23.2%
Lung	3	5.7%	8	17.4%	11	11.1%
Non-Hodgkin's	4	7.5%	0		4	4.0%

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Lymphoma						
Oesophageal	0		3	6.5%	3	3.03%
Ovarian	3	5.7%	1	2.2%	4	4.0%
Prostate	4	7.5%	1	2.2%	5	5.1%
Secondary cancers	5	9.4%	6	13.0%	11	11.1%
Unknown primary	0		3	6.5%	3	3.03%
Other	16	30.2%	14	30.4%	30	30.3%
Cancer Stage						
Pre-diagnosis	1	1.9%	1	2.2%	2	2.0%
Diagnosis-only	5	9.4%	6	13.0%	11	11.1%
In treatment	41	77.4%	32	69.6%	73	73.7%
Post-treatment	3	5.7%	2	4.3	5	5.1%
Not treatable	2	3.8%	2	4.3	4	4.0%
End of life	0		3	6.5%	3	3.03%
Not provided	1	1.9%	0		1	1.01%

This table shows us:

- The sample includes 53 patient callers and 46 callers calling on behalf of patients. The majority of callers in the latter group are relatives of cancer patients (no=28), followed by partners (no=15), and friends (no=3).
- The majority of callers are women (77.8%).
- The majority of callers identified as white British (47.5%).
- Patient callers mainly had diagnoses of breast cancer (30.2%) followed by secondary cancers (9.4%), non-Hodgkin's lymphoma (7.5%) and prostate cancer (7.5%). Relative callers mainly telephoned on behalf of patients with lung cancer (17.4%), followed breast cancer (15.2%) and secondary cancers (13.0%).
- Callers were more likely to phone as, or on behalf of, a patient currently in treatment (73.7%) compared to other stages of the illness.

The average length of the ISO calls involving patients was 7 minutes 26 seconds, and 15 minutes 54 seconds for their conversation with a nurse (total= 22 minutes 20 seconds). The average length of the ISO calls involving family and friends was 9 minutes 12 seconds, and 17 minutes 28 seconds for their conversation with a nurse (total= 26 minutes 40 seconds).

See Appendix A for a full breakdown of caller demographics based on each individual caller; and Appendix B for information about each call including their total length and the call-handlers who handled them.

2.3 Methodology

2.3.1 Conversation Analysis

These data were analysed using the principles of Conversation Analysis (CA) – a micro-analytic, qualitative methodology that conceptualises communication as a source for examining how participants, in this case helpline call-handlers and callers, accomplished various helpline-related interactional activities.

CA's approach to the study of communication is distinctive because it is a methodology and method in its own right: it comes with theoretical assumptions about viewing the world as well as procedures for data collection and analysis. The importance of studying social interaction is based on the premise that talk permeates every aspect of social life: ranging from ordinary social interaction such as catching up with a friend, talking with family members over the telephone; to talk in institutional settings, such as requesting a prescription from a doctor, or describing a burglary to the emergency services. Indeed, as Schegloff famously put it, talk-in-interaction is the "primordial site of human sociality" (Schegloff, 1992). The principle objective of CA is to discover the patterns, mechanisms and practices of talk which underlie our ability to produce and recognise meaningful social actions (Drew, Chatwin & Collins, 2000).

CA emerged in the 1960s and took two ideas from two sociologists writing at the time: 1) the idea that talk-in-interaction is a fundamental social domain that can be studied as institutional entity in its own right (i.e. that it has its own norms and practices for conduct that are independent of the people who use it), taken from Goffman (1983); and 2) the idea that the practices and procedures by which parties produce and recognise talk are talk's "ethnomethods", a shared set of resources members rely on to produce and recognise contributions to interaction which proceed in a step-by-step fashion, taken from Garfinkel (1967) (Heritage 2001, p. 52; see also Drew & Heritage, 1992, & Maynard, 2014).

CA was developed in the 1960s by Sacks, Schegloff and Jefferson who wanted to build a science of social action, and so society, by undertaking the analysis of everyday social interactions. These recordings could be subjected to

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repeated listening and examination which resulted in a steady accumulation of empirical findings that now underpin the discipline. CA uses audio and video recordings of naturally occurring interactions to enable direct observation and fine-grained analysis, focussing not only on *what* is said (the exact words used), but *how* it is said (intonation, markers of hesitation, emphasised words, overlap, laughter, crying, and so on). It is proposed that all of these features are consequential for how participants produce recognisable social actions through talk (such as invitations, requests, offers of assistance, disagreements, complaints, troubles tellings, and so on).

The audio-visual recordings are transcribed in-detail and include all aspects of verbal and nonverbal behaviour because participants used these to produce and recognise meaningful social actions in the first instance, and so they must be included in the transcription (see Appendix C for notation symbols).

Detailed transcripts play an important role in maintaining a key claim of CA that it is an inductive, 'data-driven' approach as other researchers are able to verify or refute analytic claims based on what they observe in the transcripts (Hutchby & Wooffitt, 2008).

It is worth reviewing some of the key concepts within CA because they provide an understanding of how communication operates, as well offering a useful starting point for data analysis.

1. **Turn-taking** – the most basic level of conversational organisation. This concept refers to how turns are constructed and the techniques for allocating speakership (Sacks, Schegloff & Jefferson, 1974). Turns are built out of 'turn construction units' (TCUs) which are any "sentential, clausal, phrasal, and lexical constructions" (Sacks, Schegloff & Jefferson, 1974, p. 702). Speakers are entitled to one TCU per turn. After one TCU is produced, a possible 'turn-transitional place' (TRP) is created, and the next speaker may begin their turn of talk. An understanding of TRPs is important because a delayed response after one is created can signal an upcoming dispreferred turn, such as a disagreement or resistance to advice (Schegloff, 2007). Participants use various resources to show they are going to construct a turn using

multiple TCUs such as turn prefaces, speeding up and avoiding downward intonation at these points (Clayman, 2014).

2. **Social action** – when people take turns of talk, they are doing things within that turn. A fundamental component to CA analyses is to work out and describe what social action(s) are being accomplished through a turn of talk (Drew, 2005). Social actions include requesting information, providing advice, disagreements, invitations, offers of assistance, and so on. It is important to grasp what social action is being performed because they establish a limited number of ‘conditionally relevant’ next actions (Schegloff, 2007). If a speaker performs an alternative action in response, they are usually doing something quite special, and so awareness is necessary to understand what might be going on within the talk.

3. **Turn design** – social actions can be produced in multiple ways and this is what the concept of turn design aims to describe. This component provides further understandings about what a participant is doing within their turn of talk. Social actions may be designed differently depending on the context in which they are produced. For example, Curl and Drew (2008) analysed different request forms, “*I was wondering if...*” and “*would/could you X*”, and found that their differing production was associated with the speaker’s perceived entitlement to make the request, and the perceived contingencies surrounding their request being granted. Both are doing the action of requesting but in different ways and both have different sequential implications (see below).

4. **Sequence organisation** - social actions are not produced in isolation and are instead built up over the course of the interaction, in sequences. This concept tracks the consequences one participant’s conduct has upon the others. At the most basic level, turns of talk are organised through adjacency pairs which includes a first pair part and a ‘conditionally relevant’ second pair part (Schegloff, 2007). Sequences are built out of pre, insert and post expansions, and can extend multiple turns depending on the action(s) being accomplished (ibid). This is

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perhaps one of the most important and distinctive elements to CA analyses as it facilitates an understanding about how meaningful communication was achieved over the course of the interaction (Drew, Chatwin & Collins, 2000; Stivers, 2014).

5. **Overall structural organisation** – this refers to the phase-structure of the interaction such as how the conversation was opened and closed; as well as more context-specific phases associated with interactions in institutional settings (Drew & Heritage, 1992). This is a useful tool to break-up the data into manageable sections and can help focus analyses on interesting sequences that occur within different phases of the interaction (e.g. patterns to opening interactions, how troubles tellings are arrived at and initiated, practices for advice-giving, and so on) (Jefferson, 1988; Robinson, 2014).

CA was chosen over other research methods, such as interviews with helpline participants, first because the broader helpline study incorporated this element, and second because people generally produce social actions unconsciously, without an understanding of the structures underpinning, and thus enabling, the conversation (Sidnell, 2014). Responses about interactional conduct would therefore likely be incomplete and inaccurate (Waitzkin, 1990). Audio recordings of the helpline calls were necessary to understand the detail about how meaningful communication was achieved between the participants. There exist other approaches to the study of communication, ones that apply a coding schema to the data and fit the talk into pre-existing categories, such as those used for the Roter Interaction Analysis (RIAS) (Roter & Larson, 2002) and the Medical Interaction Process System (MIPs) (Ford *et al.*, 2000). The reason for not choosing these methods rests on the well-known criticism of such coding schema - that participant behaviour is complex and cannot (easily) be fitted into a limited number of pre-determined categories (Charon, Greene & Adelman, 1994; Heritage & Maynard, 2006). Furthermore, these approaches do not facilitate understandings about how one person's communicative behaviour influences the conduct of the other – sequence organisation - because utterances are abstracted from their initial context and participant turns are coded individually (rather than how meaning was *mutually* achieved and negotiated in the building of sequences) (Stiles, 1989; Schegloff, 2007).

2.3.2 Analytic Methods

The corpus of Macmillan calls collected by the research team was large (n=326) and included a mixture of ISO-only calls and calls handled by specialist nurses. Once I was granted access to this corpus, the first task of my research was to demarcate a suitable sample of calls that could be feasibly analysed within three years to the level of detail required by CA examinations. In order to accomplish this, I took a sample of calls (n=30, roughly 10%) from this larger dataset to help facilitate my understanding of the helpline-related activities underpinning these interactions. Within this sample I noticed that there was a topical synergy within calls that were handled by nurses as they all involved discussions of medically-related problems. This contrasted to the variability within the ISO-only calls. During this period, I also noticed differences the ways the calls were brought to a close. After discussions with my supervisory team I decided to focus the thesis on the matched nurse calls (n=99) and to examine call closings further.

The sample I demarcated to use for this doctoral research was still a large number of calls to qualitatively analyse within three years and I was initially unsure about how I could examine the data in a systematic way. I decided that coding the data would provide a means to record my observations systematically and also enable me to easily navigate the entire dataset. I developed a coding framework based on my inductive examination of the calls and refined it over the course my research as my understandings about the interactional organisation of the helpline grew. Although coding may at first seem like the antithesis of conversation-analytic research, it is different to usual 'top-down' coding as the categories are grounded in the communicative conduct of the participants. Moreover, coding can be a useful way to contextualise the behaviour of the participants, especially as in-depth analyses will likely focus on a smaller subset of conversational practices (Stivers, 2015; for examples of coding within CA research see Heritage & Greatbatch 1986, Mangione-Smith *et al.* 2006, Heritage, *et al.* 2007 and Robinson & Heritage, 2014).

My conversation-analytic examinations of the data were divided into several 'steps'. Some of these steps were informed by advice from methodological

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textbooks (Atkinson & Heritage, 1984; Button & Lee, 1987; Drew, 2005; Sidnell & Stivers, 2014), and others were developed over the course of my training in CA (especially data sessions with other CA scholars). They involved: 1) repeatedly listening to the calls; 2) recording my initial observations into the coding spreadsheet; 3) applying Jeffersonian notation symbols onto existing transcripts; 4) analysing the data using the recording and the transcript with a focus on ‘social action’, ‘turn design’ and ‘sequence organisation’ (these concepts were described in the previous section); 5) discussing my analytic findings at data sessions with my supervisory team and other researchers; and 6) refining the analysis before reporting my findings in chapter form or at relevant conferences. Analyses commenced on a turn-by-turn basis for each individual call and patterns within the interactional conduct of the participants were compared which eventually formed the analytic foci of each empirical chapter.

2.3.3 Transcription

As previously mentioned, the data for this research were collected by the helpline study team prior to the start date of my PhD research. The team enlisted a highly recommended medical interactions transcription service (*CATranscription*⁵) to transcribe the calls into orthographic and Jeffersonian transcription, and this continued throughout my research. The use of this service was useful as the entirety of my corpus was transcribed; without such assistance it is unlikely I would have managed to transcribe all of the calls due to the average call length (just under 30 minutes) and instead would have carried out directed transcription to focus on particular aspects of the calls. This method is often used by scholars who work with such large corpora but it runs the risk of missing detail produced elsewhere in the interaction (Drew *et al.*, 2010). I used the transcripts provided by the service as a starting point to my own transcription but it should be emphasised that I transcribed *all* the extracts used in this thesis. I often had to add a layer of detail over the existing transcript and also changed a lot of the notation symbols used to capture aspects of speech delivery. The overall study and my research benefited from using such a service and it means that the calls could be used

⁵ More information can be found at: <https://catranscriptionservices.wordpress.com/>

again for future analyses, covering other interesting facets that I did not have time to document here.

2.3.4 Preparation for Applied Health Research

The findings from this research, as with previous work by the helpline study team (Leydon, Ekberg & Drew, 2013; Leydon *et al.*, 2013), may⁶ be used as recommendations for how the helpline could change their call-handling techniques in the future. The aims are thus comparable to objectives of ‘applied CA research’ where analytic findings are used to influence, and possibly change, the way institutional representatives deliver a particular service (see Antaki, 2011). Before I began this helpline research I briefly worked as a call-handler for a charitable health organisation in Liverpool (a much smaller charity compared to Macmillan). The timing of this role was fortuitous as it allowed me to gain experience of what it was like to be in the position of a call-handler answering calls and responding to caller enquiries. This afforded me with a strong appreciation for the skilled work call-handlers do which shaped my approach to analysis and presentation of the data at conferences, as well as how I might propose recommendations in the future (i.e. avoiding prescriptive observations about what the call-handlers *should* do and instead appreciating the difficulties associated with these kinds of roles).

2.4 Ethical Considerations

Ethical clearance was obtained from the university prior to study commencement (reference: SOMSEC060.10). This was obtained by the chief investigator (GL) for the entire helpline project during the application process in 2010. This research was undertaken in line with the Research Governance Framework for Health and Social Care (Department of Health, 2005a) and in line with other appropriate professional guidance as set by the Economic and Social Research Council (ESRC) (2015). The dignity, rights, safety and wellbeing of all participants (including researchers) are a central consideration.

⁶ It should be noted that the objective of this research first and foremost was to understand the helpline in detail because such work has not been conducted on a cancer helpline before.

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Participant **rights** were protected as they all had to provide informed consent in order to take part. All participants were asked whether they were willing to participate in two aspects of the helpline study and told this would involve: 1) the audio recording of the call being used for analysis, and 2) participation in an interview about their experience of either using the helpline (callers) or their experience of helpline work (call-handlers). Participants could choose whether they were going to take part in one or both aspects of the study. Call-handlers were recruited by the study team first. They were asked to read a study information sheet and to take some time to consider the information before returning the consent form to the research team (a freepost envelope was provided for call-handlers to do this). The information sheet described the nature of the study in detail and the contact details of the researchers were provided so that participants could ask questions about their involvement in the study if they needed to (see appendices Appendix D - F for examples of recruitment materials). The recruited call-handlers were then responsible for screening potential callers to take part in the research. As previously mentioned (pp. 28-29), Macmillan routinely record their calls and routinely ask callers about whether they would be willing to take part in future research conducted by Macmillan or other trusted organisations (such as academic institutions). This question is posed by ISOs in the first part of the call to the majority of callers apart from those who are deemed too distressed or too unwell to take part (an example of how this question is asked is provided in Appendix H, p.205). Callers are asked if they can be contacted by email or post which is then noted in a call record. Callers who agreed to have information sent by post were sent an information pack, a reply slip so they could be contacted for an interview in the future, a consent form and a freepost envelope to return their forms; all sent by Macmillan. All participants were reminded that they could opt out of the study at any time, even after this initial consent form was returned.

In order for the research team to have access to the call, *both* the call-handler and caller had to provide informed consent. Once this was obtained, a Macmillan representative provided the study team with the calls via secure electronic transfers. All participants used for this research provided informed consent for their call to be analysed and for anonymous transcripts and recordings to be presented in publications, conferences, and teaching

materials. As recommended in ethical guidelines, informed consent forms were stored separately from the data (ESRC, 2015).

In order to protect participants' **privacy**, all recordings and transcripts were stored with an anonymous label which I designed as "MCPAT1" or "MCREL2". "MC" refers to "Macmillan Corpus" so knowledge of where this data originates is transparent in this thesis and in publications; "PAT" and "REL" refer to the type of caller; and each recording was provided with a number, this further anonymising the call but facilitating easy navigation through the corpus. The ISO call contains a lot of personal information about the callers, including their names, addresses, and contact numbers. All information was changed when transcribing the calls so no transcript contains identifiable information. The service used to transcribe the calls was chosen because it is a confidential service that is accredited in handling sensitive medical materials. Personal information was silenced when presenting this work at conferences and the audio was modified so the participants' speech was unrecognisable (this was achieved by altering the pitch function in *Audacity*). Participant privacy was also ensured as the computer file containing the calls is password protected, as is the laptop the calls are stored on. Nobody has access to the laptop apart from me and it is stored securely in a locked desk along with all of the transcripts. My supervisors also have access to the corpus but they too have it stored on password protected computers.

The **well-being** of the participants was ensured as call-handlers first screened callers for their eligibility to take part in research and did not ask callers who seemed too distressed. There are some calls in the corpus which are emotionally charged and involve crying but they are in the minority and the callers eventually go on to request medical information rather than crying for the duration of the call (or becoming hysterical). The requirements of CA means that the researcher needs to listen to the calls repeatedly for analysis which can be a harbinger of stress, especially due to the topics covered and the likelihood that the researcher will have had some experience of cancer in their families/social circle. I was provided with support from my supervisors who have both worked with sensitive medical data in the past and I was made aware of a support system within the university should I require it.

Chapter 3: An Introduction to the Helpline Data

3.1 Introduction

In this chapter I discuss three inter-related matters. First, I describe how the cancer helpline calls are structurally organised, focussing in particular on the key phases and activities participants work through. Related to this I will compare how this structure compares to the structural organisation commonly found in two other social institutions - primary care visits and emergency telephone services - as these will provide an important context for understanding how the helpline operates. Second, I describe the types of support callers requested, and where within this structure their problems were volunteered (e.g. as their 'reason' for calling or as a multiple issue). Third, I describe the ways in which call-handlers frequently responded to caller' requests in the ISO and nurse calls (e.g. with information, advice or psychosocial support). The description of these three central aspects will introduce the common architecture of the calls and the activities accomplished (such as requesting advice, offering information and so on), before my three analytic chapters focus on specific problems and phases.

3.2 The Structural Organisation of Institutional Interactions

It is common practice in conversation analytic research, especially work on social institutions, to establish the overall structural organisation of the interactions under examination early on in the research process as it facilitates understandings about how the organisation operates, as well as illuminating key interactional contingencies that may influence participant participation during the encounter (Heritage, 2004; Robinson, 2014). The interactional organisation of doctor-patient medical visits in primary care, for example, are organised around a set of key activities which are conducted in the service of the broader project of diagnosing and treating people with a vast range of bio-psychosocial problems. Heritage and Sorjonen (1994) defined "activity" as: "the work that is achieved across a sequence or series of sequences as a unit course of action - meaning by this a relatively sustained topically coherent and/or

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goal-coherent course of action” (1994, p. 4). The project of the consultation, according to Robinson (2003): is “a coherent package of social action, [which] contains multiple activities” (p. 31). This activity structure is represented below in Figure 2.

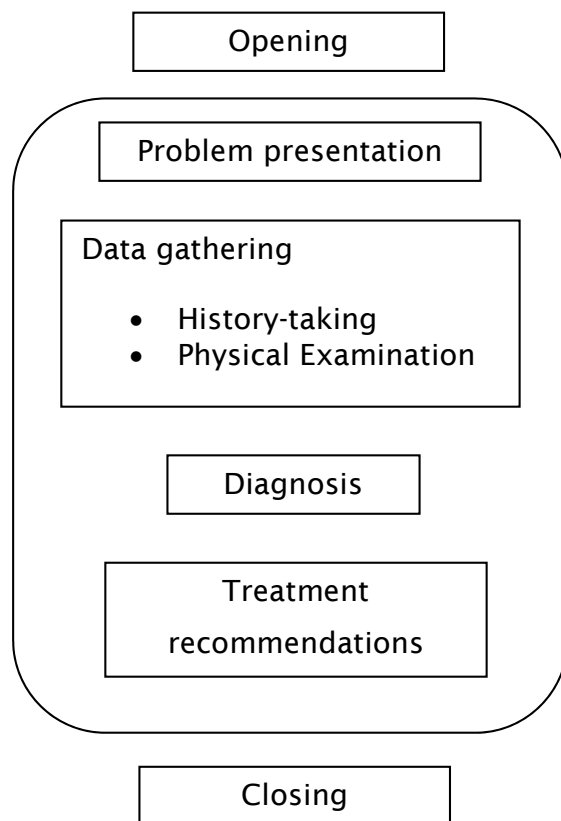


Figure 2: Phase structure of primary doctor-patient consultations, in Heritage and Clayman (2010, p. 105).

This structure has a simple functional logic in that the consultation needs to be opened and a medical problem presented before it can be diagnosed and eventually treated (Heritage and Clayman, 2010). Participants orient to these activities, and so this broader project, within their interactional conduct during such visits (Robinson & Stivers, 2001; Stivers, 2002; Robinson, 2003; Heritage & Clayman, 2010). Patients are typically provided with one clear slot to describe their medical problems as, usually, the rest of the interaction is governed by doctor initiated question-answer sequences (Maynard, 2003; Robinson, 2003; Heritage & Clayman, 2010). In terms of the importance of understanding such a structural organisation, the work to date has shown that the overall structural organisation of primary care medical visits may be one

factor that can inhibit patients from raising multiple concerns (if they have them) (Robinson, 2003; Heritage *et al.*, 2006; Heritage & Robinson, 2011).

A functional structural organisation also underpins calls to the emergency services (Zimmerman, 1992; Wakin & Zimmerman, 1999; Heritage & Clayman, 2010), shown in Figure 3.

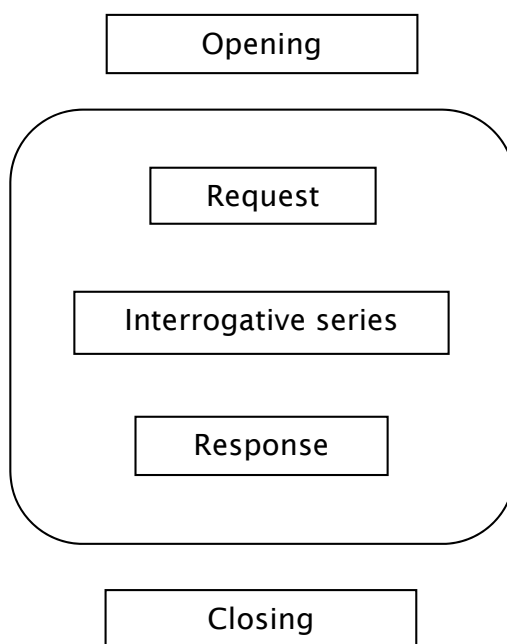


Figure 3: Phase structure of calls to the emergency services, Zimmerman (1992, p. 419).

The calls are characterised by “reduction and specialization” (Wakin & Zimmerman, 1999) which facilitates the prompt dispatch of emergency assistance. The interactions are routinely opened with an institutional identification only such as *911*, or *911 what’s your emergency* because this allows callers to formulate their request for help in few turns and it also frees the line for callers who may have dialled the wrong number (so actual emergencies can be dealt with). Callers usually produce a succinct request for help and call-handlers may ask a series of questions about the incident before a response to dispatch assistance is produced and the call is closed. Call-handlers require a problem description and information about the callers’ location before assistance can be dispatched. An extended interrogative series is thus unusual and tends to be associated with calls where this information is

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not clear or otherwise provided (Zimmerman, 1992; Heritage & Clayman, 2010).

Both doctor-patient interactions and calls to the emergency services involve the provision of publically funded services and their interactional organisation is heavily influenced by the contingency of time: primary care consultations, at least in UK general practice, are standardly organised around ten minute appointments; and call-handlers fielding emergency calls are working in high pressured (time critical) environments to ensure help is dispatched promptly. This may account for why these service providers are primarily responsible for initiating entry into the different phases of the encounters (Robinson, 2003). The contingency of time also means that both of these kinds of interactions are typically⁷ monofocal, with participants working towards the resolution of a single 'project' (Heritage & Clayman, 2010; Feldman-Kevoe, 2015).

3.2.1 The Structural Organisation of the Matched Nurse Calls

The Macmillan helpline calls are similarly organised around a number of key phases, represented here in the following diagram I designed (Figure 4). The different boxes represent the three parts of the call.

⁷I say 'typically' because patients may bring multiple concerns to discuss in primary care consultations. The broader project of diagnosing and treating medical problems still remains the same but the participants go through more of the activities outlined in the diagram based on these additional issues.

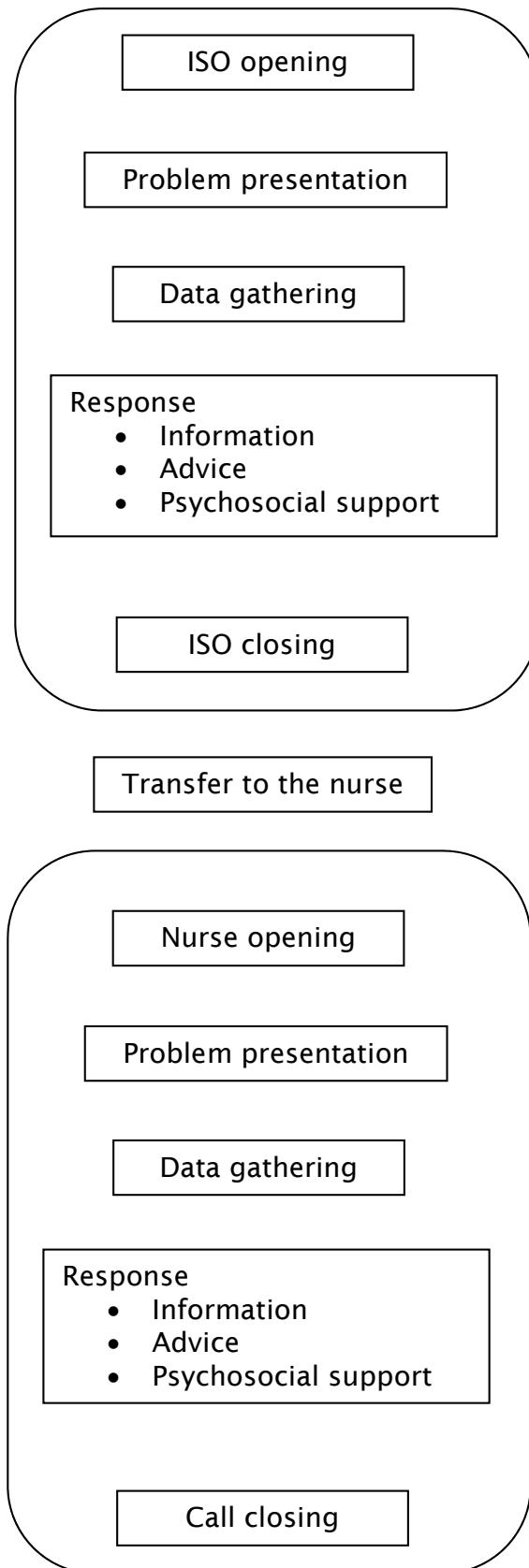


Figure 4: The structural organisation of the matched nurse calls.

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The ISOs **open** the calls with the solicitation, *you're through to Macmillan support, how can I help you*, and callers respond by presenting some kind of problem. Based on this presentation, the ISOs decide whether to handle the call themselves or to triage the caller through to a member of the welfare rights and benefits team or a cancer specialist nurse. If the ISO immediately understands that the problem is 'medical' or 'financially-related' they will inform the caller that they need to be transferred and will ask the caller a series of questions in the '**data gathering**' phase to create a new call record. The ISOs solicit both personal information from callers (their address, telephone number, date of birth and ethnicity) and they also ask two 'organisational questions' about whether the caller would like to be kept informed about the work Macmillan do for people living with cancer and whether the caller would be willing to take part in research conducted by Macmillan or other trusted researchers in the future. This information is then stored on a computer database in case the caller telephones the helpline again. Alternatively, if the caller requests psychosocial support (requests that ISOs are authorised and expected to handle) or their problem is not immediately understood as 'medical', the ISO will handle the request in the '**response**' phase. At some point during the call a decision will be made that the caller needs to be transferred to a nurse and the ISO will collect their details to create a new record (as with the other callers).

The ISO will then close the first part of the call and put the caller on hold in preparation for transfer; or they will inform the caller that a nurse will call them back within forty-eight hours. During the '**transfer phase**' the ISO will speak to a nurse and pass on minimal details about the first part of the call. These details include the caller's name, reference number from their new call record (so the nurse can update this file throughout the remaining part of the call) and a succinct summary of the caller's problem. The nurse will then take the caller off hold and **open** the second part of the call. Callers will present a problem in the '**problem presentation**' phase that may be similarly designed to the problem first presented to the ISO or, on occasion, a different problem

will be presented to the nurse call handler⁸. The '**data gathering**' phase in this part of the call involves the nurse asking the caller a series of questions about their problem before they respond to the request. This phase is similar to the history taking phase in doctor-patient interactions as it enables the nurses to collect background information (e.g. information about the patient's cancer, treatments, medical professionals involved in their care, and so on) that will enable them to respond to the caller's request. Call-handlers do not know anything about callers before they telephone the helpline, nor do they have access to patient medical records so this phase is particularly important and may extend over several turns. Once this information has been collected the nurse will provide their '**response**' which will vary between information, advice, psychosocial support, or a mixture of all three depending on what is relevant for the caller. When the caller's problem has been discussed and some form of outcome has been reached, or the nurse has informed the caller that they cannot provide the assistance they require, the participants will either move towards **closure** or the caller will raise another matter for discussion. In the latter case, the 'data gathering' and 'response' phases are repeated until the caller indicates that they have no other issue(s) to discuss.

The structural organisation of these interactions is comparable to the activities underpinning primary care visits as both involve the presentation and discussion of medically-related problems that involve one or more outcomes before the interaction is brought to a close. However, it should be noted that this schematic overview represents a simplified version of this structural organisation – in reality the calls are much more complex than primary care consultations and calls to the emergency services. This complexity is related to several factors. First, caller problems are often multifaceted and do not have an obvious resolution compared to a prescription for treatment or the dispatch of assistance which means that the participants may talk through these issues for a longer period of time. Second, and leading on from this first point, call-handlers may not be in a position to respond to caller requests based on the remit of assistance the helpline is able to provide which can have consequences for how the participants move between the phased activities and

⁸ I conducted an early comparative analysis of the problem presentations between these different phases and found that callers generally modify their presentations and provide the nurses with more information about their problem compared to ISOs.

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how the calls are eventually brought to a close. This again differs to doctor-patient interactions or calls to the emergency services because in these settings it is not that the institutional representative does not have the *expertise* to respond with the assistance requested, it is more that the problem is not serious enough to warrant medical or emergency attention. Finally, initiation into the main phase of the nurse call – the ‘business’ of these encounters – is primarily set by callers as they placed the call to the helpline. The way these interactions unfold is thus primarily related to the identity of the participants as ‘caller’ or ‘called’ rather than any other aspects of structural organisation (Sacks, 1992a).

A more detailed account about how these phases unfold, especially in the nurse part of the call, can be found in Appendix I. And, an example of a full matched call with all of these phases highlighted can be found in Appendix J.

3.3 Caller Reasons for Calling, and Multiple Concerns

Recall in Chapter 1 (pp. 11-15) that I described the large amount of cancer helpline research that has been conducted over the past twenty years. Three research themes were identified within this literature relating to caller demographics, reasons for calling and caller satisfaction. The first two themes, or research objectives, often appeared in the same study and many used similar quantitative methods to collect and analyse this kind of information, mainly ‘call enquiry forms’ and postal questionnaires (Rainey, 1985; Boudioni *et al.*, 1999; Jefford *et al.*, 2005a; La Porta *et al.*, 2005; Squiers *et al.*, 2005; Reubseat *et al.*, 2006; Dean & Scanlon, 2007; Chambers *et al.*, 2011; Ledwick, 2012). The former tool is internally created by helpline organisations to collect basic information about who is using the helpline and why, and these results are used to evaluate the demand for services and to ensure they are reaching the sectors of the population they wish to serve. The forms are designed with minimum details so call-handlers can collect this information without it interfering with their helpline work (i.e. providing callers with the help they require). Our knowledge about cancer helpline services is thus predominantly based on in-service audit/evaluations rather than in-depth scientific investigations. A possible negative consequence of this is that we have an incomplete view about the nature of these calls. Many studies, for example, have examined the reasons callers telephone cancer helplines and have

repeatedly reported that they call to discuss one concern (frequently referred to as their ‘main reason’ for calling). Little is known about the other phases of the calls apart from the opening, whether callers ring with multiple issues, and what common actions call-handlers provide in response.

MCS similarly produce annual service reports to understand who is using their service and why. These reports provide a broad overview of caller problems and they are categorised based on the first problem presented (as with the research described so far). The frequency of caller problems from 2010 (the year this data was collected) to 2014⁹ can be found in table 4.

Table 4: Overview of caller problems based on findings from the 2010-2014 MCS annual reports.

Nature of the problem	2010	2011	2012	2013	2014
DEATH AND DYING	1.8%	1.6%	1.4%	1.4%	0.9%
FINANCIAL ISSUES	18.7%	12.8%	15.1%	14.2%	10.0%
PAIN AND SYMPTOM MANAGEMENT	5.6%	6.4%	4.9%	5.2%	5.2%
PRACTICAL SUPPORT	11.8%	11.6%	12.3%	12.4%	12.5%
PREVENTION	1.0%	1.6%	2.0%	2.1%	2.3%
PSYCHOLOGICAL ISSUES	12.4%	11.5%	10.7%	10.4%	11.4%
RESEARCH AND CLINICAL TRIALS	0.3%	0.3%	0.3%	0.3%	0.2%
TREATMENT	24.4%	27.3%	31.3%	32.5%	32.5%
WELFARE RIGHT ENQUIRIES	24.0%	26.8%	22.1%	21.5%	25.0%

This table shows that callers are most likely to telephone the service about treatment-related matters, followed by welfare rights enquiries and financial issues. In regard to the nurse calls examined for this thesis (i.e. enquiries specifically related to medical matters), treatment was again the most common problem, followed by practical support and pain and symptom management.

While these categories provide a broad overview of the *topic* of the callers’ enquiry, they do not provide information about the callers’ *request* (what they wanted in regards to treatment, death and dying, and so on). Furthermore,

⁹The helpline migrated to a new call record system in 2015 and stopped producing these reports.

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there is insufficient detail about what sub-categories fall within these headings and the percentages only refer to the first problem presented.

I inductively created a framework to code the helpline calls based on my in-depth examination of the data. I identified three main categories of actions routinely used to request and deliver telephone-based cancer support which broadly fall under 'information', 'advice' and '(psychosocial) support'. I drew upon relevant conversation-analytic research to guide my categorisation of each of these actions and further developed the framework based on my inductive examination of the data.

CA studies about requesting and delivering '**Information**' and '**advice**' concur that there is a 'fuzzy' boundary between the two (Hutchby, 1995; Silverman, 1997; Pilnick, 1999). The broad definition of 'advice' described by Heritage and Sefi's research about health visiting is often used as the guide to distinguish between these two actions. According to the authors, advice is something that: 'describes, recommends or otherwise forwards a preferred course of future action' (ibid, p. 368). This definition highlights two important dimensions of requesting/delivering advice which separate it from information-giving. Advice is 'normative', as it usually imposes or prescribes a course of action that *should* be undertaken; and 'asymmetric', as the speaker providing the advice puts themselves in a more knowledgeable position than their recipient. Information is associated with describing some state of affairs in a factual way rather than recommending what the other participant should or should not do (Butler *et al.*, 2009). The boundaries of these two actions can become 'fuzzy' when advice is requested or delivered through an information-format (Kinnell & Maynard, 1996; Silverman, 1997; Pudlinski, 1998). Analysis of participant responses to these actions, both immediate and over the course of the sequence, can further promote understandings about what the action was designed to accomplish (i.e. in addition to aspects of turn design) (Pilnick, 1999).

Requests for psychosocial/emotional **support** and subsequent supportive actions come in a variety of forms within social interaction. These include (but are not limited to): an emotional tone of voice, affective lexical choices, empathic displays, crying, extended troubles tellings and laughter (see

Haakana, 2001; Ruusuvuori, 2007; Heritage, 2011; Haakana, 2012; Lindström & Sorjonen, 2014; Ruusuvuori, 2014). Supportive actions can appear in a variety of forms and can be disguised within, for example, requests for ‘information’ and ‘advice’. Recipients of these requests can also design their turns in a supportive way.

These conceptualisations were used alongside my analysis of the calls in order to create a framework to code caller requests and call-handler responses throughout the calls. If there was ambiguity about the category of the action, the participants immediate responses were analysed in order to aid clarification. Table 5 first provides the coding framework used to categorise caller reasons for calling and multiple issues.

Table 5: The coding framework used to categorise callers' reasons for calling and multiple issues within this research.

CODE	EXPLANATION OF CODE
SYMPTOM ISSUES	
Symptom management	Advice about how to manage current symptoms.
Symptom concerns	A concern or fear about the nature of current symptoms and what they represent (e.g. if they are a normal side effect of a particular cancer or treatment, or if they are abnormal and indicative of something more serious).
TREATMENT ISSUES	
General treatment information	Information about various aspect of cancer treatments including what is involved in a particular procedure or drug, how treatments work, treatment availability, future treatments, and so on.
Second opinion	The caller solicits the nurse's medical expertise (opinion) about the treatment the patient has been prescribed and whether their prescribed treatment(s) (including number of drugs, procedures, etc.) are “normal practice”.
Side effects	Information about prospective side effects that may arise from treatments and how long they typically last.
Pain and pain dosage	Questions about whether treatments will cause the pain and whether the patient's pain dosage is correct based on their stage of diagnosis. This concern is associated with relative callers only.

CODE	EXPLANATION OF CODE
Treatment other	Issues that do not fit into the above categories. For this sample this includes the location of treatments, the funding available for particular treatments and clinical trials.
PSYCHOSOCIAL ISSUES	
Emotional	Callers who are distressed (i.e. crying), either from the outset of the call or those who become upset as the interaction unfolds.
Callers who are struggling/want to talk	Callers who are finding aspects of the illness difficult to cope with and who want to talk it through with a call-handler (e.g. coming to terms with the news, coping with treatment, negative attitudes, gruelling experiences with medical care, and so on).
Disclosure of a trouble	The caller discloses some kind of trouble related to their personal circumstances or how they feel which reveals more about their reason for calling the helpline. These disclosures usually occur later on in the nurse call, after one or more issues have already been addressed.
Support/support solicited	The caller requests information about the types of support available for the patient or carer. This information is often solicited by ISOs in the first part of the call which is why it is also called 'support solicited'.
UNCERTAIN FUTURE MATTERS	
Prognosis	The caller asks for an estimate about how long the patient will live or has left to live with their particular diagnosis of cancer. The caller may also ask a prognosis-related question (e.g. if the grade of a cancer has an impact upon a patient's prognosis).
Progression	Information about how the cancer will progress in the future (e.g. the likelihood of it spreading to other organs, likely health deterioration, and so on).
Recurrence	Concerns about whether the cancer has returned or the likelihood of it doing so again in the future.
End of life (EOL)	Information about EOL including whether it will be quick, signs to look out for and what will be the cause.
MEDICAL INFORMATION (GENERAL)	
Cancer site information	General information about the patient's cancer type.
Medical terminology	An explanation about specific cancer-related terms (e.g. the difference between 'stage' and 'grade', what 'Gleeson six' means etc.).
Booklet request	Requests for a Macmillan booklet or factsheet.
FINANCE	The type of financial support available for the

CODE	EXPLANATION OF CODE
	caller (e.g. their entitlement to benefits, grants, travel insurance, and so on). Callers overwhelmingly request information about their medical problems first and raise such concerns later on in the nurse call.
OTHER	Concerns that do not fit into the above categories including questions about employment, whether it is possible to stay on a transplant list, if it is safe to visit a patient in hospital, and so on.

The calls were coded based on this framework. The framework captures the main pattern in the corpus which is for callers to initiate discussions of these matters apart from the code 'support solicited' reflects a pattern in ISO calls for call-handlers to ask carers about how they are feeling in regards to the patient's diagnosis¹⁰. The following tables will group these issues into their main category (e.g. 'treatment issues', 'symptoms', 'uncertain future matters and so on') to examine their placement between the different phases of the calls¹¹.

Table 6: Problems raised in the ISO call.

Nature of the Problem	Reason for Call		Multiple Issue 1	
	Patients	Carers	Patients	Carers
TREATMENT	n: 18 % 39.1	n: 14 % 34.1	n: 1 % 2.2	n: 3 % 7.3
SYMPTOMS	n: 6 % 13	n: 7 % 17.1	n: 1 % 2.2	n: 0 -
UNCERTAIN FUTURE M	n: 2 % 4.3	n: 7 % 17.1	n: 1 % 2.2	n: 2 % 4.9
PSYCHOSOCIAL ISSUES	n: 3 % 6.5	n: 7 % 17.1	n: 5 % 10.9	n: 11 % 26.8
MEDICAL INFO	n: 11 % 23.9	n: 5 % 12.2	n: 2 % 4.3	n: 1 % 2.4
FINANCE	n: 3 % 6.5	n: 0 -	n: 1 % 2.2	n: 0 -
OTHER	n: 3	n: 1	n: 1	n: 2

¹⁰An MCS manager discussed this with the research team and I in a meeting at the MCS office in London. She said they were going to provide ISOs with more training about how to solicit for emotional concerns because sometimes their solicitations were misplaced (i.e. the ISO asked how the caller was coping with the news but the caller had not showed any signs that they were upset).

¹¹ The issues are grouped in this way because the sample was too small to separate them into the different subheadings that fall within the same category. A table with all numbers included can be found in Appendix K and Appendix L.

Nature of the Problem	Reason for Call		Multiple Issue 1	
	% 6.5	% 2.4	% 2.2	% 4.9
DOESN'T SAY/NURSE O	n: 2 % 4.3	n: 1 % 2.4		
% callers multiple issues			n: 12 % 26.1	n: 19 % 44.2

Note: these percentages are based on the 'matched nurse calls' (the calls that involve both the ISO and nurse part of the call. The 'nurse only' calls were excluded leaving 46 patient callers and 43 friend/relative callers).

Patients presented a treatment issue most frequently as their reason for calling (39.1%), followed by a request for medical information (23.9%) and advice or concerns about current symptoms (13%). Carers also presented a treatment issue as their reason for calling (34.1%), followed by uncertain future matters (17.1%), symptoms (17.1%) and psychosocial issues (17.1%). Carers were more likely to discuss additional matters in the ISO call (44.2%) compared to patients (26.1%) and this concern was about psychosocial matters (26.8%). This difference reflects a trend in the way ISOs handle calls involving carers as they tend to ask about psychosocial matters (e.g. how they are feeling, coping with the news and so on) more often compared to calls involving patients.

Table 7 describes the frequency of problems raised in the nurse part of the call.

Table 7: Problems raised in the nurse call.

Problem	RFC		MI 1		MI 2		MI 3	
	Pat	Car	Pat	Car	Pat	Car	Pat	Car
TREATMENT	n: 19 % 35.8	n: 12 % 26.1	n: 11 % 20.8	n: 12 % 26.1	n: 16 % 30.2	n: 6 % 13	n: 6 % 11.3	n: 3 % 6.5
SYMPTOMS	n: 14 % 26.4	n: 8 % 17.4	n: 6 % 11.3	n: 1 % 2.2	n: 4 % 7.5	n: 1 % 2.2	n: 0 -	n: 0 -
UNCERTAIN FUTURE	n: 4 % 7.5	n: 12 % 26.1	n: 6 % 11.3	n: 7 % 15.2	n: 1 % 1.9	n: 6 % 13	n: 1 % 1.9	n: 3 % 6.5
PSYCHOSOC	n: 4 % 7.5	n: 6 % 13	n: 4 % 7.5	n: 9 % 19.6	n: 2 % 3.8	n: 4 % 8.7	n: 2 % 3.8	n: 2 % 4.3
MEDICAL INFO	n: 10 % 18.9	n: 6 % 13	n: 2 % 3.8	n: 2 % 4.3	n: 1 % 1.9	n: 1 % 2.2	n: 1 % 1.9	n: 0 -
FINANCE	n: 0 -	n: 0 -	n: 1 % 1.9	n: 0 -	n: 1 % 1.9	n: 0 -	n: 4 % 7.5	n: 1 % 2.2
OTHER	n: 2 % 3.8	n: 2 % 4.3	n: 3 % 5.7	n: 2 % 4.3	n: 2 % 3.8	n: 0 -	n: 1 % 1.9	n: 1 % 2.2
% callers multiple			n: 33 % 62.3	n: 33 % 71.7	n: 27 % 50.9	n: 18 % 39.1	n: 15 % 28.3	n: 10 % 21.7

issues								
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Table Key: RFC – reason for the call; MI 1, 2, 3 (multiple issues 1, 2 and 3).

Patients also presented a treatment issue as their reason for calling in the nurse part of the call (35.8%), followed by a symptom issue (26.4%) and requests for medical information (18.9%). There was thus a subtle increase in the number of symptom issues presented to a nurse which may reflect caller perceptions that the next call-handler could handle such issues (i.e. based on the ISOs description of a ‘cancer specialist nurse’). Carers presented both treatment issues (26.1%) and uncertain future matters (26.1%) as their reason for calling in the nurse part of the call, followed by symptom issues (17.4%), medical information (13%) and psychosocial matters (13%).

Both patients (62.3%) and carers (71.7%) went on to raise a multiple issue in the nurse part of the call and these were mainly treatment issues (20.8% of patients and 26.1% of carers). Patients also asked about symptoms and uncertain future matters (both 13%); and carers asked about psychosocial issues (19.6%) and uncertain future matters (15.2%). A large proportion of patients (50.9%) and carers (39.1%) raised a second multiple issue. Patients requested information about treatment (30.2%) compared to carers who wanted to discuss uncertain future matters (13%), treatment (13%) and psychosocial concerns (8.7%). Finally, a third of patients (28.3%) went on to raise a third issue about treatment (11.3%) or finance (7.5%); and carers (21.7%) raised issues about treatment (6.5%) or uncertain future matters (6.5%).

These results show that callers are likely to call the cancer helpline with multiple issues and raise most of them in the nurse part of the call. Both patients and carers overwhelmingly telephoned for information or advice about treatment, similar to findings from Macmillan’s own annual service reports (MCS Annual Service Reports 2010; 2011; 2012; 2013; 2014). Concerns of a more sensitive nature such as ‘uncertain future matters’ and ‘psychosocial concerns’ were more likely to be raised as multiple issues rather than the caller’s reason for calling, and carers were more likely to discuss these problems compared to patients. This is similar to findings from interactional research which has found that there is a preference for topics of this kind to be

'shaded' into the surrounding talk rather than volunteered as the 'reason' for the calling (Schegloff & Sacks, 1973).

In the final section I describe the ways in which call-handlers responded to these kinds of requests. For a full breakdown of caller reasons for calling and multiple issues, please see Appendix K and Appendix L.

3.4 Call-handler Responses to Caller Problems

The second aim of coding was to categorise call-handler responses into several key action types. As with the framework for caller problems, I performed this exercise in order to better understand what the helpline is used for as well as using the information to easily navigate the corpus for fine-grained analysis.

Table 8 provides an overview of the codes used to categorise call-handler responses and the sub-headings within each domain.

Table 8: Framework for coding call-handler responses to caller problems.

CODE	EXPLANATION OF CODE
INFORMATION	
Verbal information	Verbal information in relation to the caller's request.
Booklet	An offer to send the caller a Macmillan booklet or factsheet. These offers are usually placed at the end of information-giving sequences and are often used to open closing sections.
Website	The call-handler provides the name of a useful website in relation to the caller's request. The caller may be directed to this website during the call (i.e. the call-handler uses their computer to access the site too) or the caller writes down the address for use in the future.
ADVICE	
Referral to another Health Care Professional (HCP)	The call-handler recommends that the caller contact another HCP (e.g. the patient's GP, the consultant, a Macmillan nurse, and so on). The nurse may also advise the caller on what to say to this HCP in a future interaction (this was labelled as

CODE	EXPLANATION OF CODE
	'rehearsing').
Medical advice	The nurse provides general medical advice about how to manage current symptoms (e.g. clothes to wear, foods to avoid, treatments to try), dietary advice and how to prepare for future treatments.
Telephone number	The call-handler provides a telephone number of another health care professional or organisation (e.g. another helpline, the Patient Advice and Liaison Service, Cancer Research UK, and so on).
PSYCHOSOCIAL	
Emotional support or reassurance	The call-handler listens to the caller while they are distressed or provides reassurance about the nature of the caller's situation. Call-handlers sometimes display empathy during these moments too.
Name of a support group	The call-handler provides the name of a local support group in the caller's area.

Call-handlers may produce several of these responses during a single call. However, 'medical advice' and referrals to speak with other healthcare professionals are more commonly associated with actions performed by nurses in the second part of the call. There is a pattern to the placement of some of these responses. Nurses, for example, overwhelmingly provide verbal advice first and end these sequences with an offer for a Macmillan booklet or advice to visit another healthcare professional (if relevant to the caller's request). Similarly, if a caller is distressed, call-handlers will first offer emotional support before soliciting more information about the nature of the caller's problem(s) (i.e. if they have a specific medical question in mind that a nurse could answer for them). The following table provides a summary of the frequent responses produced in the ISO part of the call.

Table 9: ISO responses to caller problems.

ISO Response	Patients	Carers	TOTAL
INFORMATION			
Verbal information	n: 5 % 9.4	n: 8 % 17.4	n: 13 % 13.1
Booklet	n: 3 % 5.7	n: 1 % 2.2	n: 4 % 4
Website	n: 1	n: 1	n: 2

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	% 1.9	% 2.2	% 2
ADVICE			
Medical advice	n: 1 % 1.9	n: 2 % 4.3	n: 3 % 3
Referral to another HCP	n: 7 % 13.2	n: 11 % 23.9	n: 18 % 18.2
Telephone number	n: 6 % 11.3	n: 4 % 8.7	n:10 % 10.1
PSYCHOSOCIAL			
Emotional Support	n: 5 % 9.4	n: 11 % 23.9	n: 16 % 16.2
Name of a support group	n: 3 % 5.7	n: 0 -	n: 3 % 3

This table shows that ISOs are most likely to refer callers to another healthcare professional in the first part of the call (18.2%), offer emotional support (16.2%) and provide verbal information in relation to the callers’ requests (13.1%). These frequencies are higher in calls that involve carers and this again reflects the pattern I referred to earlier about ISOs understanding the medical nature of patient problems in fewer turns compared to calls involving carers. Nurses are more likely to produce more of these responses within the same call, shown here in table 10.

Table 10: Nurse responses to caller problems.

Nurse Response	Patients	Relative s	TOTAL
INFORMATION			
Verbal information	n: 44 % 83	n: 42 % 91.3	n: 86 % 86.9
Booklet	n: 24 % 45.3	n: 13 % 28.3	n: 37 % 37.4
Website	n: 7 % 13.2	n: 7 % 15.2	n: 14 % 14.1
ADVICE			
Medical advice	n: 13 % 24.5	n: 7 % 15.2	n: 20 % 20.2
Referral to another HCP	n: 33 % 62.3	n: 31 % 67.4	n: 64 % 64.6
Telephone number	n: 5 % 9.4	n: 6 % 13	n: 11 % 11.1
PSYCHOSOCIAL			
Emotional Support	n: 8 % 15.1	n: 12 % 26.1	n: 20 % 20.2
Name of a support group	n: 0 -	n: 2 % 4.3	n: 2 % 2

Nurses overwhelmingly provide verbal information in the second part of the call (86.9%), refer callers to other healthcare professionals (64.6%) and offer callers a Macmillan booklet or factsheet (37.4%). There are some slight differences to the way these calls are handled. Patients, for example, are offered booklets (45.3%) more frequently than carers (28.3%) and receive more medical advice (24.5% to 15.2%); and carers receive more emotional support (26.1% to 15.1%).

A large proportion of the calls thus involve the provision of verbal information and referrals to other healthcare professionals. This is related to callers' requests, both in terms of what callers asked for (most called for information about their problems) and the ones that were outside the remit of the nurses' expertise to handle (e.g. symptom concerns, providing a prognosis, the likelihood of cancer recurrence, and so on, that require a doctor or oncologist to investigate).

3.5 Conclusion

In this chapter I provided an overview about how the helpline operates, the reasons people use this service and the common actions call-handlers perform in response to caller requests. This overview helps us to understand the helpline calls in more detail, as most of the existing research has focussed on caller 'reasons for calling' and they have all used similar (basic) in-service evaluation forms to document the types of enquiries callers presented. My examination showed that there is an underpinning architecture to these calls which resembles the way doctor-patient consultations unfold in primary care; that callers typically bring two or more medical matters to discuss during these interactions; and the types of information, advice and support call-handlers provided in response to caller requests (all of which have not been documented before). I also alluded to the complexity of these calls compared to doctor-patient interactions and calls to the emergency services and argued that this complex organisation is related to the nature of caller requests (ones that may not have an obvious resolution and ones that may fall outside the remit of the nurse's expertise).

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In the next three chapters I will present findings from my analyses about *how* problems arising from a cancer diagnosis were discussed over the telephone. In Chapter 4 I begin with an examination of caller problem presentations including how they are organised and how callers requested assistance about troubling symptoms. This analysis will contribute to my first research objective about how people affected by cancer seek telephone-based support.

Chapter 4: “And I’m Feeling Absolutely Horrible”: Caller Presentations of Medical Problems

4.1 Introduction

Cancer patients and their carers telephoned the helpline to request assistance about a considerable range of medically-related matters and, as we saw in the previous chapter, many callers brought two or more problems to discuss during the call. Although the mission statement of the helpline encourages people to use the service for whatever reason they choose, even if that reason is simply to talk about matters relating to their diagnosis, both participants nevertheless oriented to a problem the caller sought help resolving. This was first evident in the opening moments of the calls, with the call-handlers’ solicitation “*you’re through to the Macmillan Helpline, how can I help you*” and the callers’ subsequent presentation of the ‘reason for calling’.

A significant proportion of callers first presented a problem relating to troubling symptoms the patient was experiencing. The symptoms were overwhelmingly physical in nature and most were causing considerable discomfort or worry for the people involved. Evidence from self-report data has found that cancer patients experience a range of different symptoms over the course of their illness with many reporting problems relating to fatigue (lack of energy, difficulty sleeping and feeling drowsy), pain, sweating and psychological distress (these problems have been reported by patients with a range of different cancer types) (Bennion & Mollasiotis, 2013; Hofsø *et al.*, 2013; Oechlse *et al.*, 2014). Although many of these symptoms are physical and therefore experienced by individual patients, there is evidence to suggest that carers of cancer patients experience the ‘symptom burden’ (Harden *et al.*, 2002; Gill, Chakraborty & Selby, 2012) arising from cancer diagnoses because they are frequently involved in symptom management (Babin *et al.*, 2008; Ross *et al.*, 2010; Badr *et al.*, 2014).

It is important to understand how those affected by cancer make sense of current symptoms because these perceptions influence when (if) medical assistance will be sought. Findings from qualitative research have repeatedly

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shown that ‘pathways to the doctor’ are multidimensional and complex, and influenced by a range of physical and social factors (Zola, 1973; Smith, Pope & Botha, 2005; Leydon *et al.*, 2009). The inability to self-manage the problem (e.g. with home remedies), the preservation and worsening of the symptom over time, and pressure from third parties (such as family members or partners) due to the negative impact of the condition upon the patient’s everyday life are common factors forming motivations to seek medical care (Zola, 1973; Leydon *et al.*, 2009; Bennion & Mollassiotis, 2013; Brunton, Booker & Mollassiotis, 2013; Whitaker *et al.* 2015). Furthermore, perceptions about whether the symptom can be accounted for in terms of ‘normal’ problems arising from a cancer diagnosis or if it is ‘ambiguous’ and potentially more serious (e.g. indicative of cancer recurrence) are also significant in terms of whether professional help will be sought (Deimling *et al.*, 2006, p. 308; Bennion & Mollassiotis, 2013). The uncertainties surrounding what symptoms may represent and the multiple problems patients may experience over the course of their illnesses led an executive report in the most recent *Cancer Patients Experiences Survey*¹² to conclude that informing patients and their families about the immediate and long-term side effects of treatment was one area of cancer care that needed to be improved (DoH 2014, p. 4).

In this chapter I will discuss how cancer patients and their carers presented troubling symptoms to a nurse. The focus on the problem presentation phase of the call will lead to a greater understanding about the callers’ reasons for seeking professional assistance and why they choose a helpline to discuss this matter. I will first review the conversation-analytic research about how people present various problems to primary care physicians and helpline organisations. Themes within this literature will facilitate an understanding about how medical problems were presented to the cancer helpline nurses as well as the resources callers drew upon to present the patient’s troubling symptoms.

¹² An annual survey run by the government to understand the needs of those affected by cancer throughout their illness including information they require before, during and after treatment has finished.

4.2 Accounting for the Visit: The Structure and Design of Patient Problem Presentations

4.2.1 Problem Presentations in Primary Care

The opening phase of doctor-patient interactions is organised around two key activities: the doctors opening solicitation (e.g. *what brings you here today*) and the patient's presentation of their medical problem (usually a description of current symptoms). The research interest in this phase has focused on the design of physicians' opening questions (Robinson, 2006; Heritage & Robinson, 2006b) and how it can influence patient satisfaction (Robinson & Heritage, 2006); as well as how patients construct professionally-relevant (Heath, 2002) or 'doctorable' problems within this context (Robinson & Heritage, 2005; Heritage & Robinson, 2006a; Heritage & Clayman, 2010). Findings from the latter tradition are substantial, and have repeatedly shown that patients draw upon several resources when describing their symptoms in such a way as to indicate that they have not entered into the 'sick role' (Parsons, 1951) lightly and are instead in genuine need of medical attention and possibly treatment (Heritage & Robinson, 2006a; Heritage, 2009; Heritage & Clayman, 2010).

According to Heritage and Robinson (2006a), people seek medical assistance for 'known' and 'unknown' medical problems. The former falls into two classes: 'routine' illnesses with which most people are familiar and which have vernacular names such as "cold", "strep throat", "flu" and so on. Routine illnesses are mild in terms of symptom experience and last only for a short period of time (usually about a week). The other class are 'recurrences' which are repeated instances of a previously diagnosed illness. Unknown medical problems, in contrast, are framed as beyond the patient's previous experience. Patients tend to describe bodily sensations which they cannot link to a specific medical condition (Heritage & Robinson 2006a, p. 50). These differing assumptions that inform primary care visits are highly significant in terms of the structural design of the problem presentation and are clearly indexed from their opening moments (Robinson, 2006). The following extract, for example, is a problem presentation of an unknown medical problem, a matter that is

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significant in terms of the resources used by the patient to describe his symptoms.

Extract 4.1

'Ringworm Expanded' (taken from Heritage & Clayman 2010, p. 129).

1 DOC: What happened.
2 (.)
3 PAT: Well I got_ (.) what I thought_ (.) in Ju:ne (.)
4 uh was an insect bite.=in thuh back of my neck here
5 DOC: Okay,
6 PAT: An' I (0.2) you know became aware of it 'cause it was
7 (itching/itchy) an'=I (.) scratched at't,
8 (0.2)
9 PAT: An' it persisted fer a bit so I tried calamine lotion,=
10 DOC: = Okay,
11 (0.2)
12 PAT: An' that didn't seem to make it go away completely, an'
13 it=s:tayed with me,=w'll its still with me. Thuh long and
14 thuh short of it.
15 DOC: [Okay.]
16 PAT: [Cut to thuh] chase is its- its still with me, .hhh but
17 (its) got a welt associated °with it.°
18 DOC: Okay,
19 (0.5)
20 PAT: Its got a welt that's (.) no:w increased in size to about
21 that big=it was very (.) small [like a di:me] initially
22 DOC: [Okay,]
23 PAT: you know, an' now its (0.3) like a (.) bigger than a half
24 do:llar (I bet [it's like-]) [()-]
25 DOC: [And you] [said it's] no: longer
26 itchy. Is that correct,

The following analysis will address three salient points about this extract which are important in terms of understanding how medical problems are presented to primary care physicians.

1. The patient 'packages' his presentation in a narrative format as this enables him to describe the key events that led to his current appointment. He shows he is going to do this at the start of his

presentation with the preface “well” (Schegloff & Lerner, 2009) and his time reference to last June (line 3). Heritage and Clayman (2010) note that problem presentations may also be structured using a [headline] + [expansion] format in which a patient will succinctly describe their problem at the start of the presentation and expand on the details over the course of a narrative. This format similarly allows for a patient to describe the chronology of events informing their visit (see Heritage & Clayman, 2010, p. 109 for an example).

2. The resources invoked throughout this presentation form a creditable account for seeking medical attention. This is accomplished with his reference to his ‘first thoughts’ (lines 3-4), a normalising device that shows that he did not jump to erroneous conclusions about the cause of the problem (c.f. Jefferson, 2004b; Pollner, 1987; Sacks, 1984); his mode of symptom discovery (lines 6-7), that he only noticed the symptom when it started to become itchy rather than actively seeking medical problems by some means of body hypervigilance or paranoia (Halkowski, 2006); and in his description of a self-management technique (line 9), that he tried to resolve the problem himself before seeking professional help (c.f. Jefferson, 1980 on ‘troubles resistance’).

3. All of these reasoning processes justified the patient’s reason for the visit; namely that the problem persisted over time despite his intervention and has since increased in size (*it’s like bigger than half a dollar*, lines 23-24) and provenance (*it’s got a welt associated with it*, line 20) (Heritage & Clayman, 2010). Patient problem presentations often culminate in present day descriptions of current symptoms, a point that is understood by both participants as the end of the problem presentation phase (evidenced here at lines 25-26 when the doctor asks his first history-taking question) (Robinson & Heritage, 2005). For a further discussion about why the distinction of ‘known’ and ‘unknown’ medical problems is important see Pomerantz (2002) on ‘lay diagnoses’, Stivers (2002) on the difference between ‘symptoms-only’ and ‘candidate-diagnosis’ problem presentations, and Heath (2002) on how patients with mild complaints (e.g. sore throats, coughs, headaches, and

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so on) use gestures to turn seemingly trivial medical problems into more serious, doctorable ones.

Most of the research on problem presentations has focussed on how patients themselves describe their symptoms in doctorable ways (Heath, 2002; Pomerantz, 2002; Halkowski, 2006; Heritage & Robinson, 2006a; Heritage & Robinson, 2006b; Chatwin *et al.*, 2014). The little evidence there is about how people present medical problems on behalf of patients has shown that they draw upon different resources to justify the reason for the visit. A recent paper by Lee and Kim (2015), for example, found that patient problem presentations to emergency triage nurses were short and tended to be simple descriptions of pain (e.g. *stomach hurts*, p. 580). Carer presentations, in contrast, were longer, as they provided more background information about what they had observed or know about the patient's medical history (e.g. previous prescriptions) to communicate the relevance of seeking emergency care. Lee and Kim (*ibid*) theorised that this added more creditability to the carers account because it focussed on 'objective' measures of what they could see or know rather than delving into the subjective realm of pain (which they did not have the epistemic access to describe) (c.f. Pomerantz, 1980; Heritage, 2011; 2014). Drew (2006) similarly found that carer problem presentations of medical problems in out-of-hours GP calls included more background information about why the symptoms were alarming and so a cause for concern. They would only change their initial descriptions to convey the serious nature of the problem if they perceived the doctor's questioning was heading in the direction of a "normally unwell" outcome (i.e. on that would not result in a home visit).

4.2.2 Presenting Problems to Helpline Organisations

There is more variation in the type of problems presented to helpline organisations and this relates to the variety of services on offer from these institutions (Baker, Emmison & Firth, 2005). This variation has an impact upon how these interactions are opened as well as the resources people use to present their 'reason for calling'. Danby, Baker and Emmison (2005) and Emmison and Danby (2007), for example, examined calls to a children's helpline and identified a three-part structure to the way problems were presented to this organisation. This structure consisted of a 'greetings

exchange', a 'troubles announcement' and 'reason for calling', as the following extract shows.

Extract 4.2

Opening sequence of calls to a Kids Helpline (taken from Emmison & Danby 2007, p. 8).

1 CT: Hi Kid's Help Line,
 2 (0.2)
 3 C: -> .hh hi Um gidday how are you,
 4 CT: Hullo (.) good thanks,
 5 C: -> Um look (.) I'm just a bit worried right now .hh
 6 CT: Mm hm,
 7 C: I'm in a stage of my life (0.2) where I'm um (.)
 8 developing (0.4) I don't know (.) different like to the
 9 rest of the boys in my class?
 10 CT: Mm,
 11 C: A:and I (.) it's sort of becoming like (0.4) I wait for
 12 them (.) to get to me (0.2) and tease me?
 13 CT: Okay,
 14 C: It's become really irritating now,
 15 (0.2)
 16 CT: °Right°,
 17 (1.0)
 18 C: -> I dunno what to do.

The call-handler opens the call by stating the name of the organisation only (line 1) rather than soliciting the caller's problem and the pair exchange greetings (lines 3-4). Emmison and Danby (2007) argue that the design of this opening turn reflects the mission statement of the helpline which is to *listen* to caller problems rather than to intervene or otherwise resolve them. The caller then 'announces a trouble' about being teased by other boys in his class (lines 5-14) and ends his presentation with a request for advice about what to do about it (this forming his 'reason for calling'). Shaw and Kitzinger (2007b), similarly identified an overarching structure to the way callers presented their problems in calls to a Home Birth helpline, problems which included a desire for a home birth (*well basically I would like a home birth*), an obstacle to that desire being granted (*but my GP isn't that keen*) and a request for information or advice (*So I just wondered you know how would I go about it if my GP isn't*

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really keen) (ibid, p. 4). The explicit request for information or advice at the end of caller presentations is a key difference to the way problems are presented to primary care physicians.

Callers may invoke several resources during these presentations to construct their problem(s) in a professionally-relevant (Heath, 2002) or helplineable way. For example, Potter and Hepburn (2003) found that callers to the National Society for the Protection and Prevention of Cruelty to Children (NSPCC) frequently began their reports of child abuse or misconduct with “*I’m a bit concerned...*”. The authors argued that this practice displayed an appropriate caller stance toward the problem they were reporting (i.e. that their motivations for getting involved were for a genuine concern about a child rather than reporting misconduct maliciously to get somebody in trouble) as well as an appropriate reason to contact a helpline rather than the emergency services (ibid). Edwards and Stokoe (2007) found that callers to a neighbourhood mediation service would often describe how they tried (and failed) to self-manage the problem on their own before contacting the service. As with patients in primary care, this justified their reason for calling because the caller’s inability to resolve the dispute left them to endure problems with their neighbours (which could turn nasty depending on the reason for the quarrel, similar to symptoms worsening if left untreated). This work drew heavily upon early work by Sacks (1967) who found that callers calling a psychiatric hospital would justify their call, and reason for wanting to commit suicide, by claiming they had “no-one to turn to”; a device to account for why they could not improve the situation on their own.

4.2.3 Summary

In summary, patients and callers overwhelmingly present one problem during the opening phase of the interaction and construct it in ways that are suited to the particular services on offer from that organisation. The structural design of the presentation enabled the participant to describe key decisions informing their help-seeking behaviour such as their attempts and inability to manage the problem on their own, the persistence of the problem over time and their lack of knowledge about how to resolve the situation (Sacks, 1967; Robinson & Heritage, 2005; Halkowski, 2006; Heritage & Robinson, 2006a; Edwards & Stokoe, 2007; Shaw & Kitzinger, 2007b). The resources invoked differed

depending on whether the participant was describing their own experience or the experience of others (Pomerantz, 1980; Drew, 2006; Heritage, 2011, 2014; Lee & Kim, 2015).

While findings from this research are informative, there is little research about how *medical* problems are presented to helpline organisations, or how people describe symptoms arising from a *serious* known medical problem such as cancer. The few studies about cancer specifically have focussed on how patients talk about their fears and uncertainties about the *future* (rather than current symptoms) (Beach & Dozier, 2015), and how doctors manage cancer patients' presentations of pain in order to offer relevant cancer treatments (rather than exploring the subjective experience of the pain itself) (Rogers & Todd, 2000). The aim of this chapter is to contribute to this evidence gap by focussing on how symptoms arising from a confirmed diagnosis of cancer were presented to nurses on a cancer helpline. The analysis will focus on: 1) the resources callers used to describe symptoms arising from a known medical problem; 2) how they compare to what we know about symptom descriptions in primary care; and 3) whether there were differences to the ways in which patients and carers described symptom experience.

Before focusing on symptom descriptions specifically, I will provide an overview of how caller presentations of medical problems were routinely structured. This structure applies to both patient and carer problem presentations in both parts of the call, regardless of what their particular enquiry was about.

4.3 Establishing the Reason for the Call: The Structure of Caller Problem Presentations

The problem presentation phase in these cancer helpline calls was defined as the callers' communication beginning after the nurses' opening solicitation of a problem and ending at the nurses' attempts to shift out of this phase onto a different activity (Heritage & Robinson 2006b, p. 98). My in-depth analysis found that problem presentations to a nurse were overwhelmingly constructed using three components: 1) a medical history; 2) a problem construction; and 3) a request for information or advice, represented here in the following

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diagram (the colours for each component will subsequently correspond with the extracts).

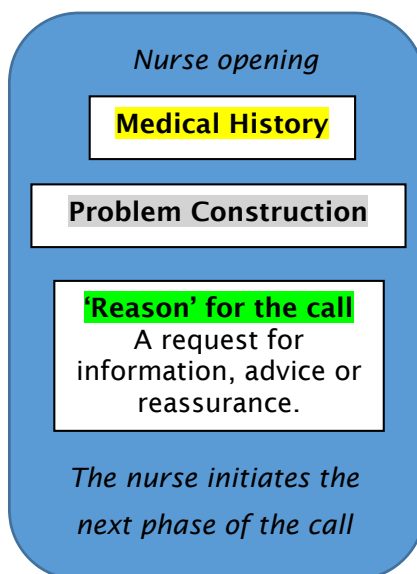


Figure 5: The structural organisation of the nurse call opening sequence.

This structure, as it appears here, accounted for 59.6% of caller problem presentations in the corpus. There were two main variations to this design: 1) the nurse opened with a summary of the callers 'reason for calling' resulting in the caller expanding on certain parts of their presentation (known as the nurse summary format) (23.2%); and 2) the caller provided a succinct summary of their problem at the start of the presentation before expanding on the details using these three components (known as the [headline] plus [expansion] format) (14.1%). Even with these slight variations in design, though, callers used the above components to build their problem presentations, they just might have placed them in a different order or one component might have been excluded. There were two cases within this collection that did not fulfil the inclusion criteria for this analysis. Both involved the nurse asking a series of questions after their opening solicitation rather than providing the usual 'slot' for the caller to present their medical problem. The pair still orientated to a problem the caller needed help resolving but this was discussed during a question-answer sequence. The analysis was thus based on 97 opening sections.

I will now provide an example of each format. The caller in the first extract is a male cancer patient who was diagnosed and treated for non-Hodgkin's

lymphoma several years ago. This presentation is structured using the three components outlined above.

Extract 4.3

PAT19/Nurse8, Patient problem presentation [3 components structure], [0 - 01:23].

1 N: Oh hello is that ((name)) [speaking,]
 2 C: [Oh yes, H]ello (dear/there)
 3 N: Oh: hello, you're through to one of the nurses
 4 [on ou::r] tea::[:m.] Hello.
 5 C: [Mm right.] [Um:]
 6 C: In two thou:sand I: had non-Hodgkinson lymphoma .hh
 7 N: Right=
 8 C: =And I was successfully treated.
 9 N: Ri:ght.
 10 C: Two years ago, (.) I had a cavernoma (0.2) which is a bleed
 11 on the brain. A a defo::rmed blood vessel.
 12 (.)
 13 N: Mm hm,
 14 C: U::m, (0.4) this year I had a heart attack (.) A::nd one
 15 of the consultants, (.) has suggested, (.) >a:nd this is
 16 what I am thinking< (.) and that, (.) the possibility of
 17 spla:sh (.) from the radiotherapy treatment I received (.)
 18 may be responsible (.) for the, (.) the:: the:: (.)
 19 problems (1.2) .hh Do you feel there may be anything in
 20 that?

Transcription note

- Line 6 - this is how the caller pronounces his cancer type. The official name is spelled and pronounced non-Hodgkin's lymphoma.

After the nurse showed recognition of the caller and identified herself as “one of the nurses” (lines 1-4), the caller began his problem presentation by providing a medical history. This included: when he was first diagnosed with cancer, the name of his particular cancer type, that he was treated successfully and two health problems (a bleed on the brain and a heart attack) he has endured since finishing treatment (lines 6-14). The patient used a timeline to describe these problems which started in 2000 and slowly culminated into the present day with a reference to “two years ago” (line 10) and then “this year” (line 14). He showed that he was going to move onto the next presentational component with his use of “and” (line 14) and presented a problem about an

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accident that occurred when he received radiotherapy treatment several years ago. He explained that the treatment, rather than targeting the cancerous area, may have accidentally hit, or “splashed”, the surrounding normal tissue and this, he has been told, may have caused his more recent medical problems. The caller ends his presentation with a request, “.hh Do you feel there may be anything in that?” (lines 19-20), a turn that is essentially asking the nurse – another healthcare professional – for a second opinion about what he has been told by one of his consultants.

The next problem presentation is similarly structured except the caller described her ‘reason for calling’ at the start of the presentation and this acted as a ‘headline’ to the details she goes on to describe over the course of the presentation. The nurse returned this call to a female patient with breast cancer.

Extract 4.4

PAT24/Nurse3, Patient problem presentation, [Headline] + [Expansion] format, [0 – 01:34].

((Phone ringing))

1 C: Hello?

2 N: Hi is that ((name))?

3 C: Yes that’s ri:ght.

4 N: Hi ((name)) this is ((name)) I’m one of the:: um
5 information nurses on Macmillan’s helpline a [collea]gue
6 C: [O:::h.]
7 said you’d ca:lled.

8 C: Oh thank you <for ca:lling me back> [thank y]ou.

9 N: [°O↓kay°]

10 C: U::m (.) I (.) I I just had some (.) questio:ns about
11 chemotherapy I[’ve](.) just had my we::ll (.) e::r about
12 N: [Okay,]
13 C: (.) two wee:ks >ago now< .hh I had my third cycl::e of
14 chemotherapy,
15 N: [Mm hm,]
16 C: [And um] (.) .hh I’ve just come out of hospital I wa::s er
17 (.) with neutropenic sepsis,
18 N: °Oka::y°
19 C: A:nd I’m feeling very ti:red and (.) and very lo:w at this
20 point=and I didn’t even know what it wa::s u:m (.) before

21 I went into hospital .hhhhhh An I'm just not (0.4) °coping°
 22 very well with the chemo,
 23 N: Ah ha,
 24 C: full stop. Um I want to stop it (.) but-
 25 N: °Oka::y,°
 26 C: I don't know whether (0.4) that would be very <dangerous>
 27 to do (.) #o::r# whether (0.6) I (.) i- it I: just don't
 28 kno:w=I just wondered if I .hh (0.4) having had three::
 29 cycles I'd have some protection,
 30 N: Mm mhm, °Mm hm.°
 31 (0.6)
 32 C: But- #A::# and whether maybe other people maybe feel the
 33 same as I: do. I don't know ha:lftway through. .hhh

The caller first provided a succinct summary of her request, “U::m (.) I (.) I I just had some (.) questio:ns about chemotherapy” (lines 10-11). This turn does capture why she was telephoning the helpline but it was lacking in detail, or “granularity” (Schegloff, 2000), about the specific questions she wanted to ask about her treatment and why. This is what she went on to describe using the three components. She first provided a medical history (lines 11-17) which focused on the number of chemotherapy cycles received, the timing of this treatment and a serious infection she contracted while in hospital. The details provided by this patient differed to the ones provided in extract 4.4, showing that callers designed the medical history component in relation to the problem(s) they went on to construct (i.e. they did not provide the patient’s full medical history, just the salient aspects related to their reason for calling). This medical history fed into her problem about feeling ‘very tired’, ‘low’ and not being able to ‘cope’ with the treatment (lines 19-24). The patient ended her presentation with a request for information about whether it would be possible for her to stop treatment at this point (lines 26-33); and this provided the details behind the headline she produced at the start.

The final extract illustrates how these opening sequences unfolded if a nurse began the call with a summary of the caller’s ‘reason for calling’.

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Extract 4.5

Rel37/Nurse1, Carer problem presentation, [Nurse summary] + [expansion format], [0 - 00:42].

1 N: >↑Hello misses< ((name) you're speaking to ((name)) I'm one
2 of the nurses here at >Macmillan cancer support< <I
3 understand your husband's been diagnosed with prostate
4 cance:r and you've got some questions about the treatment
5 that he's being offered how can I he:lp
6 C: .hhhh Well, (0.6) we'd just li:ke s:ome informa:tion
7 plea:se on h- .HHHHH (.) he:::, (0.4) is terrified of
8 incontinence
9 N: M:::n,
10 C: E:::rm (.) a::nd when we we::nt (0.6) #e:::r# to see the
11 consultant before christma::s .hhh
12 N: Mm::
13 C: The only o:ne that they do the:re i:s (.) the radiatio:n?
14 N: Mm:::,,,
15 C: but, (0.4) >I mean< I've read that, (.) pla:ce there's
16 places where you can have it with a gri::d (0.6) and there,
17 (.) there are other treatme::nts

The nurse summarised part of the patient's medical history, ("I understand your husband's been diagnosed with prostate cance:r") and the caller's reason for calling ("and you've got some questions about the treatment that he's being offered") (lines 2-5). Note that the problem informing the caller's 'reason for calling' was absent from this summary and this is what the caller provided in her expansion. The caller self-repaired from producing a request to constructing a problem, ".hhhh Well, (0.6) we'd just li:ke s:ome informa:tion plea:se on h- .HHHHH (.) he:::, (0.4) is terrified of incontinence" (lines 6-8), and thus displayed an orientation to the importance of providing such details before formulating a request. The caller continued describing the problem (lines 10-13) and finally ended her presentation with an 'indirect' request for information.

In summary, caller' presentations of medical problems were typically structured using three components: 1) a medical history, 2) a problem construction and 3) a request for information or advice. Both participants oriented to the importance of these details which was represented in the

frequency of this design within the corpus and the components used by nurses in their opening summaries. This structural organisation closely resembles the way patients describe medical problems to primary care physicians (Heritage & Clayman, 2010; Heritage & Robinson, 2006a; Heritage & Robinson, 2006b; Robinson & Heritage, 2005) and the way people establish their ‘reason for calling’ to helpline organisations (Danby, Baker and Emisson, 2005; Emmison & Danby, 2007; Shaw & Kitzinger, 2007b). The key difference to patient problem presentations in primary care was the inclusion of a medical history. This component is important as it shows that the patient had a confirmed diagnosis of cancer (i.e. a “known medical problem”) and it also informed the nurses about relevant details they may have needed in order to respond to the callers’ requests (contrasting to primary care physicians who have access to patient medical records during the consultation).

Now that I have examined the overall structural organisation of caller problem presentations, I will examine the practices used to present a frequent and important concern for callers about the patients’ current symptoms.

4.4 Problem Presentations about Current Symptoms

23% (no=23) of callers telephoned the helpline to request information or advice about physical symptoms the patient was experiencing. The presentations fell into two categories: callers who wanted symptom management advice, and callers who expressed concern about the nature of the symptom(s) experienced. Here is a short definition of each:

1. **Symptom management**– callers overwhelmingly¹³ described one physical symptom that was causing discomfort or pain for the patient and requested information or medical advice about how the severity of the symptom could be reduced.
2. **Symptom concerns** – callers presented with one named symptom or they described a bodily sensation the patient was experiencing. These

¹³ Overwhelmingly’ because some callers described more than one current symptom (although this happened infrequently with the most describing one, similar to patients in primary care).

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presentations ended with an expression of concern about the nature of the symptom or, with carer callers, a concern for the welfare of the patient. The ‘concern’ may have been expressed using language associated with ‘being concerned’ such as ‘concern’, ‘worry’, ‘fear’, ‘scared’, ‘panic’ and so on, or a request for information about the normality of the symptom.

The following table provides an overview of the callers within this collection including salient aspects about their medical history, the nature of the symptom described and what they requested from a nurse.

Table 11: Sample description of callers presenting with symptom problems.

No.	Caller	Medical History	Symptom Issue
Patients			
1	PAT 1 Nurse6	Prostate cancer In treatment – Zoladex injections.	Hot flushes Advice about how to manage current symptom.
2	PAT 3 Nurse8	Prostate cancer Recently stopped a course of Zoladex treatment.	Night sweats Distressed about severe nature of symptom and worried he is starting to smell.
3	PAT 10 Nurse16	Breast cancer In treatment – chemotherapy.	Mouth ulcers Advice about how to manage current symptoms.
4	PAT 34 Nurse14	Non-Hodgkin’s lymphoma In treatment – chemotherapy.	Fatigue Information about tiredness and nutrition.
5	PAT 44 Nurse1	Breast cancer Had a mastectomy and is currently on chemotherapy.	Sweats Information about how to manage sweats.
6	REL 32 Nurse13	Bowel cancer Third cycle of chemotherapy.	Diarrhoea Advice about how to manage current symptom.
7	PAT 4 Nurse8	Bowel cancer Recently had an operation.	Pain in side Concerned about whether the pain is a pulled muscle or something more serious.
8	PAT 9 Nurse3	Breast cancer Recently changed chemotherapy drugs.	Undefined symptom (‘feeling horrible’) Wants to know if her symptoms or related to treatment or “something else”.
9	PAT 11 Nurse3	Breast cancer Just finished chemotherapy.	Hair growth Starting to worry that she is

No.	Caller	Medical History	Symptom Issue
			growing a beard and wants to know if the tablets could be causing it.
10	PAT 13 Nurse8	Breast Had cancer 5 years ago.	Pain in leg Concerned her symptom is a sign of cancer recurrence.
11	PAT 20 Nurse4	Breast Had surgery 2 months ago and finished radiotherapy 10 days ago.	Exhaustion Describes intense exhaustion since finishing her treatment.
12	PAT 22 Nurse6	Chronic Lymphatic Leukaemia Second course of chemotherapy.	Range of symptoms (constipation, perforation in nostril, sleep problems, phlegm) Wants to know if his tablets are causing these symptoms to worsen.
13	PAT 23 Nurse2	Breast cancer In treatment – chemotherapy (aromatase inhibitors).	Stiffness in hands Wants to know if her symptoms are normal (or “common” in her words).
14	PAT 25 Nurse15	Skin cancer Waiting for an operation to be scheduled.	Painful lump on arm Concerned about time between appointments based on severity of the lump.
15	PAT 39 Nurse8	Breast cancer Finished treatment 2.5 years ago.	Fatigue and weight loss Wants to know if her symptoms are normal based on how long ago she finished treatment.
Carers			
16	REL 1 Nurse1	Lung cancer Had surgery.	Shortness of breath Advice about how to manage current symptom.
17	REL 10 Nurse4	Oesophageal cancer Third cycle of chemotherapy.	Hiccups Advice about how to manage current symptom.
18	REL 18 Nurse8	Breast cancer Chemotherapy.	Burning pain throughout digestive system and weight loss Concerned about the patient’s welfare and wants to know how ‘best to advise’ her about eating and the weight loss.
19	REL 32 Nurse13	Bowel cancer Third cycle of chemotherapy.	Diarrhoea Advice about how to manage current symptom.
20	REL 9 Nurse1	Unknown primary (secondary cancers in stomach and glands)	Face distortion Wants to know if her mother’s symptoms are normal or a sign

No.	Caller	Medical History	Symptom Issue
		Started a new chemotherapy tablet.	the treatment is not working.
21	REL 28 Nurse1	Stage four lung cancer Palliative radiotherapy.	Range (weight loss, breathlessness, coughing) Concerned for the patient's welfare if her returns home after treatment based on his range of symptoms.
22	REL 35 Nurse17	Possible lung cancer N/A.	Coughing up blood Concerned about the patient based on the severity of her symptom and the lack of help from A & E.
23	REL 45 Nurse2	Oesophageal Waiting for treatment, had a feeding tube fitted.	Lightheaded and sleeping more often Wants to know if symptoms are 'usual' or if the family should be worried about it.

The majority of callers were telephoning as, or on behalf of, a patient currently in treatment (15/23), and most telephoned to express concern about the current symptom(s) (14/23).

The following paragraphs will address two key aspects about these problem presentations: 1) the interactional resources used to describe current symptoms by patients and their carers, and 2) the design of caller requests for symptom management advice and expressions of symptom concerns.

4.4.1 Symptom Descriptions

Patients tended to present current symptoms using descriptive terms that conveyed their arduous experience of the symptom, or the unusual nature of the symptom itself, and both could appear within the same presentation. The caller in extract 4.6, for example, a male patient with prostate cancer, used such terms to convey the severity of his hot flushes.

Extract 4.6

MCPAT1/Nurse6, Patient symptom description, [0 - 00:31]

- 1 N: Hello:: you're through to a nurse:, how can I hel:p.
2 C: .tchhh Hell:o. ((clears throat)) U::m .hh (0.4) I have
3 been di:agnosed with er prostate cancer?=A:nd .hh <I've::>
4 been on medication the twenny one day: tablets before I- I

5 recci- I received .hhh my first (.) er: implant injection
6 er Zoladex?
7 N: Mm hm?
8 C: ((clears throat)) An:d I've:: (.) uh:: (.) to date I've had
9 two injections .hh last one was la:- Tuesday there. .hh
10 [((clears throat))] And er: .hh what I'm suffering from,
11 N: [Mm hm,]
12 C: (0.3) #I:# obviously I'm- I'm s(h)ure yo(h)u ge(h)t .hh hot
13 flushes?
14 N: ↓Yea:[:h,
15 C: [((clears throat))] An' av' just been readin'...

After the nurses opening solicitation (line 1) and the patient's description of his medical history (lines 2 -6), he moved on to present a problem about hot flushes. This symptom was presented using the descriptive term "suffering", a term that captured how the flushes were burdening him (i.e. he did not just present 'hot flushes' and instead described himself as *suffering* from them).

The use of this language was a robust pattern across patient problem presentations. The patient in extract 4.7, for example, provided a succinct presentation about "suffering" from mouth ulcers.

Extract 4.7

MCPAT10/Nurse16, Patient symptom description, [0 - 00:13].

1 N: Hallo::?
2 (.)
3 C: Hello.
4 N: Hi: there ((name)) >is it i- i-< it's er: ((name)) you're
5 through to: ho[w °can I-°
6 C: [Oh hi: ((name)) hi. .hh U:[m (0.3)
7 [°how are you
8 today:..°
9 C: ↓Yea::h I:: oh. I've been suffering um: .tch >most
10 of the weekend< with the most horrendous mouth ulcers: and
11 my mouth's really sore:.
12 (.)
13 N: Mm hm,
14 C: .tch And I just thought . . .

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This patient did not provide a medical history and instead presented a problem only (recall in section 4.4, p. 76 I explained that these components could appear in a different order between each presentation or be absent completely). She used the same descriptive term to describe her mouth ulcers (*I've been suffering*), which again referred to her experience of the problem; and constructed their severity by describing them as the “most horrendous mouth ulcers:” (line 10) and the pain stemming from them, “my mouth’s really sore:” (line 11).

The patient in extract 4.8 also provided a succinct problem construction, this time of “feeling absolutely horrible”.

Extract 4.8

MCPAT9/Nurse3, Patient symptom description, [0 - 00:27].

1 N: ↑Hi: ((name)) you're talking to ((name)) I'm one of the
2 nurses, can I hel:p?
3 C: .hhh Oh hello, .hh yea:h. I've um:: (.) had breast cancer I
4 was operated on in Ma:y and I've been undergoing
5 chemotherapy,
6 N: Mm hm,
7 C: .hhh last week I changed from f e c: to: <Her:ceptin .hhh
8 and Do:cetaxel>
9 N: Aw:kay, °o[kay.°
10 C: [And I'm feelin' (.) absolutely horrible and I
11 (.) don't know. . .

This patient used a simple descriptive term to convey how ‘horrible’ she was feeling generally rather than naming a specific symptom like the callers in the previous extracts. This again referred to the severe impact of the problem upon her general well-being.

Patients thus described current symptoms using various linguistic terms which conveyed the severity of their symptom or arduous symptom experience, and these were generally placed near the start of their problem presentations. The resources used closely resembled what Pomerantz (1986) called “extreme case formulations”. According to Pomerantz, such formulations are recurrently used to legitimise a claim about some object or state of affairs. A speaker accusing

another or ruining a recently purchased item of clothing, for example, might emphasise that the dress was not just “new” but “*brand* new” to justify their expression of anger and request for reimbursement (ibid). The use of these formulations by the patients here captured the severe, or ‘extreme’, nature of the symptom to a participant who did not have visual access to the symptom being described. This language also conveyed the severity of their problem and warded off potential counter claims from the nurse that they were regular side effects of the patient’s current treatment; an endeavour particularly important for a diagnosed cancer patient who will experience many symptoms over the course of their illness.

Carer problem presentations, in contrast, included more background information about how they knew the symptoms were severe and possibly a cause for concern. This may have been achieved by using the same descriptive terms as with patient problem presentations, but they were produced over the course of a presentation rather than at the start. The caller in extract 4.9, for example, the daughter of a female patient, produced a lengthy problem presentation about her mother’s increasing sickness and weight loss.

Extract 4.9

MCREL18/Nurse8, Carer symptom description, [0 - 01:39].

- 1 N: Hello there ((name)) you’re through to one of the nurses,
- 2 C: He::llo hi thank you f[or tak]ing my call.
- 3 N: [↓Hi::.]
- 4 N: Not [at a:ll.]
- 5 C: [.h h h h]h h h e- (.) Yeah. >I-< We’re j[ust] trying to
- 6 N: [(?)]
- 7 C: wor:k out the best thing.=I’ve run:g I’ve rung:: ((name of
- 8 organisation)) (when) Mum was under their care::.
- 9 N: Mm[:::,
- 10 C: [.hh to speak to one of the nurses.
- 11 N: M[m hm,
- 12 C: [.h h h U::m (.) but she’s just- she’s (0.2) she:: was
- 13 diagnosed in::(.) ((noise in background)) in two thousand.
- 14 =sorry I’ll just turn that off.
- 15 (.)
- 16 N: Mm hm,
- 17 C: She was diagnosed in:: u:m August a[n:d she’]s basically::

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- 18 N: [Mm ↑hm,]
- 19 C: u:m, .tch halfway through her chemotherapy and she's
20 changed sessions.=>Amount of the type< of chemotherapy it
21 i:s.
- 22 N: Mm:::,
- 23 C: U:m .hh but she's she's (.) obviously had increased
24 symptoms of burning all: down through her digestive
25 system: .hhh which is really like causing an awful lot of
26 discomfort:.
- 27 N: Ri:ght.
- 28 C: .hh U::m a:nd yesterday my da:d gave her some:: some pasta
29 and she felt like it was almost sticking her insides
30 together and she was sick.
- 31 N: ↓Mm[::, (.) ↓mm]:.
- 32 C: [U::m (.)] I was saying to your colleague >°you
33 know°< she'll: .hh sometimes with her di:et she hasn't
34 always eaten the best things >(though)she can be a little
35 bit faddy?
- 36 N: M[m: hm,]
- 37 C: [.hhh] U::m (.) so I ta:lked to her and said that I
38 sugge:st that >you know< she speak to the:: the dietician
39 at the hospital about that.
- 40 N: Mm:?
- 41 C: An' basically get some advice on the best way to eat
42 things.=and maybe[: .hhh] some supplements would be
43 N: [Mm:,]
- 44 C: helpful coz sh- I think s[he lo:st half a]sto:ne within
45 N: [Mm °hm, ° °mm hm°]
- 46 C: three weeks. .hhh And she [start]ed looking frai:l and
47 N: [°Ye.°]
- 48 C: you're like that- mu:m that's not (.) not okay.
- 49 N: M[m:,
- 50 C: [.hhh Um- if you're strugglin' to get things down you need
51 to:: .hhh eat the best things possible so we- y[ou]need to
52 N: [Mm,]
- 53 C: some advi:ce on that.
- 54 N: [Mm hm, mm:
- 55 C: [.hhhh She's- u::m I spoke to her earlier on today an' my
56 sister's:- has spoken to her as we:ll and she's just y[ou]
57 N: [Mm,]
- 58 C: know really really tearfu::l.

59 N: Mm hm,
 60 C: U:m feeling just like completely (.) terrible [um]really
 61 N: [Mm,]
 62 C: really sick. [.hhh so she's] talked to the hospital about
 63 N: [↓Ohh (°dear°)]
 64 C: her sickness symptoms and she's wai[utin]g for them to come
 65 N: [Mm,]
 66 C: back to her: .hhh
 67 N: Mm hm,
 68 C: But what we're: we're really concerned...

At line 23 the caller began to describe the patient's symptoms about increased burning down her digestive system which she described as: "but she's she's (.) obviously had increased symptoms of burning all: down through her digestive system: .hhh which is really like causing an awful lot of discomfort" (lines 23-6). Although the severe nature of the symptoms is emphasised with her use of "really" and "awful lot" the actual problem – discomfort – was a weaker version of how this symptom could have been described (i.e. an awful lot of *pain*). She subsequently provided more background information about the patient including her recent problems with eating and sickness (lines 28-30), her well-known irregular eating habits (lines 32-35) and her weight loss (lines 44-46). It is only after this information was provided that the caller conveys how severe and how gruelling the patient is finding her current symptoms, "she's just y[ou] know really really tearfu:l. U:m feeling just like completely (.) terrible [um]really really sick." (lines 55-62). The severe nature of the problem was thus delayed within a longer narrative and evidenced considerably throughout. By "evidenced" I mean that rather than succinctly describing that the patient felt terrible, as with patient problem presentations (e.g. *I'm feeling absolutely horrible*, extract 4.8), she provided more background information about the patient as well as how she knew something was wrong with reference to third party observations (see lines 28 and lines 55-56 respectively).

The caller in extract 4.10, the daughter of a male patient, similarly provided evidence for her claim that the patient's current symptoms were a cause for concern by referring to what she had been told by a third party. This caller also described how she knew the symptoms were different, and so more alarming, compared to ones previously associated with his cancer diagnosis.

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Extract 4.10

MCREL45/Nurse2, Carer symptom description, [0 - 00:48]

1 N: .tch .hhh ↑Hi: you're through to one of the nurses, my
2 name's ((name)) how can I he:lp you.=
3 C: =Oh: hello there. .hhh U::m .hh >yeah sorry< I just spoke
4 to one of your collea::gue[s u::m .hh]I was just gonna
5 N: [.tch Mm hm,]
6 C: as:k your advice about my da:d really. [U::m (.)] .tch he's
7 N: [°Mm hm, °]
8 C: got a pe::- >he's got oesophageal< cancer:. He[: - he]has a
9 N: [Mm hm,]
10 C: pe:g at the mome::nt, [.hhh] u::m that he's- been havin'
11 N: [Mm hm,]
12 C: u::m >having to have< six for:tisips a day: through that.
13 N: Mm hm,
14 C: U::m .hhh but toda::y, u::m (.) I don't actually live
15 with him >but I've< been on the phone to my mu:m
16 ((swallows)) and she said (?) he's rea:lly not feeling too
17 well today. .hhh he is u::m (.) .tch very li:ght headed,
18 N: M[m hm,]
19 C: [And h]e's been sleeping.
20 N: Mm hm,
21 C: >On and off< for most of the da:y. Well that's not been
22 li:- >I mean he's only< had the peg for two: weeks but
23 that's not actually been: .hhh h[e's been:] .hh >don't
24 N: [Mm hm,]
25 C: me< =wro::ng he's been very tired and,
26 N: M[m hm,]
27 C: [>you know< bu:t n- but not like this: and I have been
28 trying to phone..

The caller first described the patient's symptoms in reference to what she was been told by her mother in a recent telephone call. Note that she self-repaired from immediately describing the patient's symptoms ("but toda::y, u::m...", line 14) to explaining where her knowledge came from ("I don't actually live with him >but I've< been on the phone to my mu:m...and she said...", lines 14-16); which provided more evidence about how the family knew something was wrong (i.e. she reported observations from somebody who had direct access to the patient). The patient's symptoms were initially described using weak

descriptive terms, “he’s really not feeling too well today.” (lines 16-17), and then upgraded with references to feeling “very light headed” and sleeping more often during the day (lines 17-21). The caller relied on the nurse to infer the seriousness of the latter symptom as it is associated with cancer progression (especially end of life). It is only in her comparison that the caller displayed her knowledge of why these new symptoms were alarming and in need of professional evaluation, “Well that’s not been li:- >I mean he’s only< had the peg for two: weeks but that’s not actually been: .hhh h[e’s been:] .hh >don’t he’s been very tired and, [>you know< bu:t n- but not like this:...” (lines 23-27).

The caller in the final example, the daughter of a male patient with lung cancer, described the severe nature of the patient’s symptoms only after the nurse asked more details. This caller similarly used a comparison of the patient’s health before the onset of his recent medical problems which feeds into her construction about how she knew the new symptoms were concerning.

Extract 4.11

MCRel28/Nurse1, Carer symptom description, [0 - 01:30].

- 1 N: ↑Hello ((name)) you’re speaking to ((name)) I’m one of the
 2 nu::rse::s how can I help.=>I understand< your fa:ther’s
 3 had some treatment for lu:ng cancer and you’re wondering
 4 about further treatment?
 5 C: U:m yea:::h I mean he’s had palliative radiotherapy for
 6 fi:ve days u::m ((clears throat)) and now he wants to go
 7 home.=He has been staying at my .hhh sister’s hou:se.
 8 N: Ri:ght.
 9 C: U:::m (0.2) .tch (.) >and he’s< only just finished the
 10 radiotherapy.=>I mean he< ↑wants to go home and basically
 11 he is going ho:me because he’s still very (.) u:m hu::h .hh
 12 he’s well in his head.
 13 N: Mm ↑h[m,
 14 C: [Anyway. And he wants to go home and that’s it.
 15 However, .hh we were: >sort of under the impression that
 16 it would get< (.) slightly wo::rse (.)th[e aft]er
 17 N: [Mm:::] effects
 18 C: before it got (.) any bette:r. .hhh U:::m, (.) and I know
 19 everybody’s different but w- wou:ld he be: expected do you

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20 think to get (.) kind of slightly worse: over this weekend:
21 or:
22 N: .HHHH .pt I mean it's really difficult to sa::y I think y-
23 I think it's just that you ↑have to be aware that sometimes
24 when people have radiotherapy:: y- they- they can get an
25 increase:ing (0.2) >you know their- their< symptoms can
26 increa:se a little bit so .hhh so what sort of symptoms had
27 he got in the fir::st pla:ce.
28 C: [E:r breathlessness:[he's]
29 N: [Nyea::h]
30 C: very wea:k he's lost an aw:ful lot of wei:ght. >He's
31 probably< [.hh s] even stone or therea↑bouts:.
32 N: [mm::,]
33 N: Mm[: ,
34 C: [.hh U::[m] >he was never< very big by the way bu:t seven
35 N: [M]m:
36 C: stone he's just like a- [.hhh (.)] stick really. .hhh U:::m
37 N: [Mm::,]
38 C: (.) .tch a:::nd hh I think he's been coughing more since he
39 star:ted the radiotherapy but [I >don']t know whether<
40 N: [Mm::,]
41 C: that's .hhhh rela:ted.
42 N: [And how far away is his ho::me
43 from: (.) [fr-
44 C: [from me: i[t's about (.)] °four miles.°
45 N: [(to go from-)]
46 N: And from his dau:ghter's where he is staying now:.

The problem first presented (lines 14-18) was a concern for the patient's welfare if he returned home alone after his radiotherapy treatment. It was only after the nurse solicited more details from the caller ("so what sort of symptoms had he got in the fir::st pla:ce.", lines 26-7), that the caller expressed her concern. These symptoms were constructed using extreme case formulations (Pomerantz, 1980), "E:r breathlessness he's very wea:k he's lost an aw:ful lot of wei:ght." (lines 28-30), and her comparison explained why these new symptoms were concerning, "U:::m >he was never< very big by the way bu:t seven stone he's just like a- .hhh (.) stick really." (lines 34-36).

In summary, patients and their carers drew upon different interactional resources when presenting current symptoms to a nurse. Patients were more likely to use construct the severity of their symptoms near the start of their presentations and this formed the problem construction component; contrasting to carers who provided more background information about how they knew the new symptoms were a sign of health deterioration and possibly a cause for concern. These findings are similar to those by Lee and Kim (2015) who found that carer problem presentations to emergency triage nurses were longer than patient presentations as they provided more background information to justify their reasoning for seeking emergency care. The authors theorised that these differences were related to “epistemics of experience” (Pomerantz, 1980; Heritage, 2011, 2014) whereby people describe problems based on what they have appropriate access to describe (i.e. carers can legitimately describe what they can see rather than pain the patient is feeling). The resources used in caller problem presentations related to the knowledge base of the different callers but also to how callers conveyed that the symptoms were more unusual or severe to the ones previously associated with the patient’s cancer diagnosis (i.e. their ‘known medical problem’).

All problem presentations ended with a request for assistance about how to reduce the severity of the symptom or to express concern about what it might represent. It is the design of these requests to which I now turn.

4.4.2 Requests for Assistance

The majority of callers within this collection were telephoning the helpline to express concern about the symptom experienced (14/23). These concerns were first expressed using the resources outlined above and also within the callers’ requests for assistance. These concerns were related to the normality of the symptom and whether it was a usual part of a cancer diagnosis or something more serious in need of professional evaluation. Before I examine these cases, though, I will briefly explain how callers formulated requests for symptom management advice. The turn design of these requests will help us understand how concerns arising from a known medical problem were expressed.

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Requests for symptom management advice typically included a description of how the caller had previously tried to self-manage the symptom prior to contacting the helpline. These resources appeared within both patient and carer problem presentations. The caller in extract 4.12, for example, a male patient with prostate cancer, referred to a booklet he consulted before placing his call (the start of this presentation first appeared on p. 84).

Extract 4.12

MCPAT1/Nurse6, Patient request for symptom management advice, [00:19 - 00:49].

8 C: ((clears throat)) An:d I've:: (.) uh:: (.) to date I've had
9 two injections .hh last one was la:- Tuesday there. .hh
10 [((clears throat))] And er: .hh what I'm suffering from,
11 N: [Mm hm,]
12 C: (0.3) #I:# obviously I'm- I'm s(h)ure yo(h)u ge(h)t .hh hot
13 flushes?
14 N: ↓Yea:[:h,
15 C: [((Clears throat)) And I've just been reading >th- the
16 y-< your little pamphlet that says ↑cut down on tea and
17 coffee. .hh Well I don't drink coffee but (.) I would- ↑not
18 drink a lot of tea but I drink tea:.
19 N: Mm h[m,
20 C: [.hh And is there any ↑other ways to sorta (0.7) >uh<
21 to:: sorta (0.3) uh- cut those dow[n. A] a little bit?

After describing his current symptoms (lines 12-13), the patient referred to advice he obtained from a Macmillan booklet (see the reference to *your little pamphlet*, line 15) about how to reduce the severity of hot flushes. He explained that the advice obtained from this source was not relevant to his situation because he does not consume enough hot beverages for them to be causing the problem (lines 15-18). This description fed into the formation of his request for “other ways” to reduce his current symptoms (i.e. different suggestions to the ones he found in this pamphlet). The request was mitigated with the use of “sorta” and “cut those down a little bit”, a turn design that oriented to: a) his awareness that his problem could be reduced rather than resolved completely (i.e. it is a side effect that many men with prostate cancer have to endure); and b) his expectations about what the nurse could provide in response.

This pattern of referring to self-management techniques and mitigating request designs was a pattern within other problem presentations for symptom advice. The patient in extract 4.13, for example, asked the nurse for suggestions about how to better self-manage her mouth ulcers (the start of this presentation can be found on p. 85).

Extract 4.13

MCPAT10/Nurse16, Patient request for symptom management advice, [00:10-00:29].

9 C: ↓Yea::h I:: oh. I've been suffering um: .tch >most of the
 10 weekend< with the most horrendous mouth ulcers: and my
 11 mouth's really sore:.
 12 (.)
 13 N: Mm hm,
 14 C: .tch And I just thought .hh well I'm doing what I::
 15 ca:n >I thought well is there anything< (.) that you might
 16 suggest in terms of (.) >you know what< to do: to try and
 17 .pt:: clear them u:p and:: >you know< ↑how to manage it
 18 really. .hhh
 19 N: Mm hm,
 20 (0.5)
 21 N: .pt E:::r how long have you been o::n the: chemotherapy.

Although this caller did not specify what exactly she had been doing (*And I just thought well I'm doing what I can*, lines 14-15), she nevertheless referred to aspects of self-managing her problem before formulating a request (and so placing her call). This request was also mitigated several times in ways that similarly oriented, as with extract 4.12, to the nature of her problem (i.e. whether such symptoms could be “cleared up”) and her expectations about what the nurse could provide (*I thought well is there anything that you might suggest in terms of what to do to try...*). An alternative and more direct request might have been designed as, *what can I do to get rid of them?*

Finally, on a slightly different track, the caller in extract 4.14, a husband who enquired about his wife's breathing problems, explained that he had been unable to contact a medical professional involved in the patient's immediate

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care (lines 12-15) and this informed his request for symptom management advice.

Extract 4.14

MCREL1/Nurse1, Carer request for symptom management advice, [00:38-01:33].

- 1 N: ((name)) you're speaking to ((name)) I'm one of the
2 nu::rses here:: I understand your wife's had some surgery
3 for lu:ng cancer how can I he::lp.
- 4 C: Ri:ght well basically love u::m (0.3) we- w- we recei:ved
5 a letter fro:m the: hospi:al rega::rding he::r (.) u:::m
6 (0.4) sort of e::r condition and tha:t. .hhh
- 7 N: Mm::,
- 8 C: An::d asking us to: >fill in< a questionnaire etcetera
9 etcetera. .hhh U::m about being introduce:d to the:: uh
10 cancer ↑nu:rse (.) specialist.
- 11 N: Mm::,
- 12 C: Well, (.) e::r the wife never has bin.
- 13 N: Mm:[:,
- 14 C: [Has never been to:ld how: to contact them o::r anything
15 li:ke that. .hhh
- 16 N: ↑Mm,
- 17 C: BASically what I'm looking for:: is to:: is is:: e::r e-
18 ↑anything that I: can do: or we can do: to impro::ve, .hhh
19 her general health and her brea::thing etcetera etcetera.
- 20 N: Mm::, Mm:. .hh And when did she have the surger:y:?

The design of this request was mitigated with the use of the negatively polarised, “↑anything that I: can do: or we can do: to impro::ve...” (line 18). This design, as with the other callers, constructed the request in a helplineable way as it focussed on improving her health rather asking for treatment.

Descriptions of self-help have been found in problem presentations to physicians in primary care (Halkowski, 2006; Heritage & Clayman, 2010) and helpline organisations (Sacks, 1967; Edwards and Stokoe, 2007). These authors argued that the use of such descriptions justified the patients', or callers', reason for the visit because they provided evidence of how they tried (and failed) to manage the problem on their own before requesting professional assistance. In terms of the callers here, their inability to self-manage their

problems had left the patient with severe symptoms to endure and this provided an account to their request for further (professional) help. The callers mitigated the design of their requests so their symptom descriptions were in pursuit of services on offer from a helpline, an organisation that can offer information and advice rather than diagnose and treat medical problems.

Callers who expressed concern about current symptoms did not include such descriptions of self-management techniques. They may have referred to other health care professionals they had previously tried to contact but not how they tried to reduce the symptom itself. There was more variation in what the callers requested at the end of these presentations but many asked the nurse to assess the seriousness and/or the normality of the symptom endured. The patient in extract 4.15, for example, succinctly described her symptoms before asking the nurse about whether she should make an appointment with a doctor (the start of this presentation first appeared on p. 86).

Extract 4.15

MCPAT9/Nurse3, Patient symptom concern, [00:19-00:37].

10 C: [And I'm feelin' (.) absolutely horrible and I
 11 (.) do::n't know if my symptoms are due to the che:mo o:r
 12 whether (.) I've got something else that I: .hhhh need to
 13 (.) sort of see a ↑doctor about.

The patient expressed concern about the seriousness of her symptoms by referring to an ominous “something else” her symptoms may represent (line 12). Furthermore, her request for advice about whether she needed to visit a doctor further constructed a concern about these symptoms because she was considering making an appointment to have them evaluated.

Other callers similarly expressed concerns about the seriousness of the symptoms by asking the nurse to evaluate the extent of the problem. The caller in extract 4.16, a daughter calling about her father's increasing symptoms, asked for advice about whether the family should be worried about his recent health deterioration (the start of this presentation first appeared on p. 90).

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Extract 4.16

MCREL45/Nurse2, Carer symptom concern, [00:35-01:13].

- 19 C: [And h]e's been sleeping.
- 20 N: Mm hm,
- 21 C: >On and off< for most of the da:y. Well that's not been
22 li:- >I mean he's only< had the peg for two: weeks but
23 that's not actually been: .hhh h[e's been:] .hh >don't
- 24 N: [Mm hm,]
- 25 C: me< =wro::ng he's been very tired and,
- 26 N: M[m hm,
- 27 C: [>you know< bu:t n- but not like this: and I have been
28 trying to phone the .hhh the Macmillan nurse at the:
29 hospital: w:['oo-] >who normally hel:ps us< but it's
- 30 N: [Mm hm,]
- 31 C: just been on ans:wer phone >and I haven't been able< to
32 hol::d of her. .hhh
- 33 N: Mm hm,=
- 34 C: =So I- (.) I didn't want to ring the GP coz: (0.4) to be
35 quite honest with you: they've not been much help to us
36 anyway.
- 37 N: M[m hm,
- 38 C: [.hhh So I just thought I'd give yourselves a ring to see
39 if you could give us:- .HH I mean is this a usua:l thing
40 that happens:, or: is- >should we be worried< about
41 it.=Should I be speaking to someone I'd- I- (.) not quite
42 sure::.. .hhh

The caller explained that she initially tried to contact the patient's Macmillan nurse about the change in her father's condition but was unable to reach her on this occasion (lines 27 – 32). She also explained why she had not visited the patient's GP and both of these accounts fed into her concern that the patient's new symptoms were different to the ones he had experienced previously and her reason for contacting the helpline specifically. Her concern was further expressed in the articulation of her request as she asked for information about whether the symptoms were "usual", if the family should be worried and if they should seek further assistance (lines 38-42).

Finally, the caller in extract 4.17, a daughter calling in regards to her mother, asked the nurse for advice about what the family should do to manage the patient's medical problems.

Extract 4.17

MCREL18/Nurse8, Carer symptom concern, [01:37-02:04].

- 68 C: But what we're: we're really concerned >my mum's< not a big
69 lady anyway::s li[:ke] th- the weight and the eating, .hhh
70 N: [Mm:]
71 N: Mm h[m, mm hm,]
72 C: [An- (.)] just the increased symptoms and it's w- w-
73 what[s be:]st to advise her to do:.
74 N: [°Ye.°]
75 N: ↓Mm::,
76 C: I'm- >I'm quite< happy to speak to her GP: or: you know
77 N: Mm::,
78 C: As as a family we'll do whatever we ca:n for her:
79 b[ut we']re just trying to think what's be:st to do:.
80 N: [Mm hm,]
81 N: .tch Nyeah, yea:h. .hh w- whe::n e- did y- could ya (.) w-
82 whe:n (0.2) when was your mum diagnosed ((name)).

This caller requested advice about what was “best to do” based on the patient's erratic eating habits and increased weight loss (this was described in the problem construction component of her presentation, see extract 4.9 p. 89 - 90). Similar to the callers in the other extracts, this caller oriented to the seriousness of the problem by referring to the patient's GP (line 76) and in her request which asked the nurse to recommend an appropriate course of action (line 79).

In summary, callers telephoning the helpline with concerns about current symptoms overwhelmingly asked the nurse to assess the seriousness of the problem. There was an absence of referring to self-management techniques within these presentations which added to the callers' concerns that the symptom was different to ones they, or the patient, had previously experienced (i.e. they did not know how to manage it). This justified the callers' reasoning for seeking professional assistance from a helpline because

the patient was left with severe symptoms to endure and did not know if they were a usual part of their diagnosis or indicative of something more serious.

4.5 Conclusion

The objective of this chapter was to examine how problems arising from a serious known medical problem (a cancer diagnosis) were presented to nurses on a cancer helpline. There are three significant findings from this research. 1) There was a robust three-part structure to the way medical problems were presented. The medical history component marked the identity of the caller as someone who had or knew a person with a confirmed diagnosis of cancer. 2) There were key differences to the way the different callers presented the patient's troubling symptoms: patients typically produced succinct accounts of their symptoms and used various linguistic resources to convey their severity; while carers provided more background information about how they knew the symptoms were different, and so alarming, to ones previously associated with the patient's diagnosis. These resources conveyed the seriousness of the problem to nurses who did not have visual access to the patient or access to their medical records. The resources also warded off potential counter claims from the nurses that the symptoms were regular side effects cancer or its treatment. 3) Finally, I examined caller requests and showed that most people telephoned the helpline to express concerns about the symptoms experienced and frequently asked the nurse to evaluate the seriousness or normality of the patient's problem. A key feature of these presentations was that they did not include descriptions of how the caller had tried to self-manage the problem prior to calling the helpline (i.e. with home remedies or literature) which fed into their concern, and 'reason for calling', that the symptom was unusual or more alarming than ones the patient had previously encountered. Overall, these findings led to a greater understanding about how medical problems were presented on a cancer helpline and the concerns informing people's decisions to seek professional assistance about troubling symptoms arising from a diagnosis of cancer.

This chapter also pointed to a problem brought to the helpline that the call-handlers might not be equipped to discuss (i.e. in order to fully evaluate the seriousness of the problem the nurse would need to perform a physical examination). In the next chapter I will discuss another frequent concern

discussed during these calls about the patient's prognosis. This analysis will build upon this research as it will include a description of how problems are volunteered by callers at later points in the interaction rather than just at the beginning; and the resources used by call-handlers to respond to such requests.

Chapter 5: Uncertain Future Matters: Prognosis Requests and their Management

5.1 Introduction

The problem described by the caller - either the problem they indicated was their 'reason for calling' or one they volunteered later on during the call - may have been relatively straightforward and required the provision of information; or it may have been more complex, of an emotional nature, or even outside the remit of services on offer from the helpline. The symptom concerns described in the previous chapter were one class of caller problems that could cause communication difficulties for the participants over the course of the interaction because the nurses were not in a position to diagnose the patients' current symptoms, and so the callers' expectations may not have been fulfilled. Requests for a prognosis were also difficult for nurses to discuss for the similar reason that call-handlers do not have the information, expertise or resources to deliver prognoses for the caller/patient over the telephone.

A prognosis, as defined in medical terms, is: "An assessment of the future course and outcome of a patient's disease, based on knowledge of the course of the disease in other patients together with the general health, age, and sex of the patient" (Oxford University Press 2010, p. 597). Research has shown that informing those affected by cancer about the patient's future can lead to positive clinical and quality of life outcomes including the development of appropriate treatment plans; an enhanced sense of control; acceptance and preparations for end of life; and improved bereavement outcomes for caregivers (Hagerty *et al.*, 2005b; Hancock *et al.*, 2007b; Innes & Payne, 2009; Walczak *et al.*, 2013; Applebaum *et al.*, 2014). However, while there is consensus that this information is important, communicating prognoses has been described as complex (Clayton, Butow & Tattersall, 2005; Almack *et al.*, 2012; Walczak *et al.*, 2013; Cartwright *et al.*, 2014; Johnson *et al.*, 2015). This complexity is related to several factors including: varying information preferences, the clinical difficulty of determining proximal outcomes for cancer, and the lack of evidence-based guidelines about how to facilitate such discussions (Kaplowitz *et al.*, 1999; Butow *et al.*, 2002; Hagerty 2005b; Parker

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et al., 2007; Kaplowitz, Campo & Chiu, 2009; van Vilet *et al.*, 2013). As a result of these difficulties, patients' and caregivers' needs for this information, similar to concerns about troubling symptoms (Chapter 3), frequently remain 'unmet' (Adams, Boulton & Watson, 2009; Finney-Rutten *et al.*, 2005; Harrison *et al.*, 2009; Janda *et al.*, 2008; Lambert *et al.* 2012; McCarthy, 2011).

A significant proportion of callers telephoned the helpline to enquire about uncertain future matters including requests for a prognosis (i.e. a timeline about how long the patient would likely live), this possibly reflecting their inability to obtain this information elsewhere. In this chapter I will examine these requests and the ways in which nurses frequently responded. My analysis will show that nurses often encounter problems during these discussions and reveals also the reasons for the occurrence of such trouble. In the next section I will review relevant literature about the challenges of discussing the patient's future in various healthcare settings as well as how medical professionals broach these topics during real-time consultations.

5.2 Difficult Conversations about the Patient's Future: A Review of Relevant Literature

5.2.1 Evidence from Self-Reported Data

Many of those affected by cancer want prognostic information, but they vary in their preferences for how they want this information communicated and at what point in their illness trajectory (Clayton, Butow & Tattersall, 2005; Parker *et al.*, 2007; see also Leydon *et al.*, 2000). Individual preferences vary considerably but many studies have reported that patients and caregivers want to be 'ready' for the discussion (Walczak *et al.*, 2013); that the information should be provided gradually (Cartwright *et al.*, 2014; Parker *et al.*, 2007); that it should be delivered by a doctor whom they know and trust (Hagerty *et al.*, 2005a; Johnson *et al.*, 2015); and that the doctor should be open/honest but careful not to diminish hope for the future (Butow *et al.*, 2002; Clayton, Butow & Tattersall, 2005; Hagerty *et al.*, 2005b; Innes & Payne, 2009; Parker *et al.*, 2007). Furthermore, preferences for information may change as a result of treatments or disease progression, leading many studies to suggest that doctors should ask patients and caregivers about the type and depth of

information they would like to receive (Butow *et al.* 2002; Clayton, Butow & Tattersall, 2005; Back & Arnold, 2006; Parker *et al.*, 2007; Cartwright *et al.*, 2014).

Systematic literature reviews have reported that doctors are comfortable discussing diagnoses with cancer patients but less comfortable discussing prognoses, despite patient preferences for this information (Hagerty *et al.*, 2005; Hancock *et al.*, 2007a; Hancock *et al.*, 2007b; Applebaum *et al.*, 2014). Concerns about patient welfare and their ability to understand complex information influences the type of information doctors will give (if at all) and how they will deliver it (e.g. quantitative or qualitative prognoses, the use of jargon, positive statements, and so on) (Hagerty *et al.*, 2005b; Hancock *et al.*, 2007a; Innes & Payne, 2009; Slort *et al.*, 2011; van Vilet *et al.*, 2013; Johnson *et al.*, 2015). Moreover, in a qualitative interview study by Butow *et al.* (2002) medical professionals pointed to the “ambivalence” surrounding prognosis questions, suggesting that while patient/caregivers may *appear* to be asking for a proximal estimate, they may in fact be seeking hope and guidance about the impact of the disease on their lives. Straightforward questioning about information preferences, while seemingly ‘ideal’, may thus in fact be too much of a “simplistic approach” for delivering this information (ibid, p. 164).

Self-report studies about prognosis discussions have agreed that the ability to deliver this information skilfully and sensitively is very important (Hagerty *et al.*, 2005b; Cartwright *et al.*, 2014; Johnson *et al.*, 2015). However, there is a discernible evidence gap about what doctors and patients *actually say* during these conversations (Rodriguez *et al.*, 2007) and how such ‘sensitivity’ could be achieved in practice. An in-depth examination of this talk will offer an important contribution to the existing literature about communicating prognoses because many recommendations for practice arising from this research are based on idealist assumptions about what *should* happen during these discussions rather than what can realistically happen based on empirical evidence of real communication practices.

5.2.2 Conversation-Analytic Studies

A variety of studies about language and social interaction in healthcare have examined how ‘difficult’ future topics (Parry, Land & Seymour, 2014) are

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discussed in doctor-patient consultations, including those involving cancer patients (Luftey & Maynard, 1998; Beach 2002a; 2002b; 2003; Maynard, 2003; Beach & Good, 2004; Rodriguez *et al.*, 2007; Leydon, 2008; Rodriguez *et al.*, 2008; Beach & Dozier, 2015; Maynard, Cortez & Campbell, 2016; Pino *et al.*, in submission); patients with AIDs (Peräkylä, 1993, 1995; Silverman, 1997; Silverman & Peräkylä, 1990); psychiatric patients (Bergmann, 1992); as well as how bad news is discussed more generally (Freese & Maynard, 1998). Many studies have focussed on the language used during these interactions and how this reflects the participants' orientations to the 'sensitive' matter being discussed (i.e. the challenges outlined in the previous section).

Beach (2002a; 2002b; 2003) examined a collection of telephone calls between family members as they talked about the various illness dilemmas associated with a diagnosis of cancer; from news of the patient's diagnosis to news about her terminal prognosis once the cancer had spread. He found that the family would routinely use technical/biomedical language to discuss updates about the patient's deteriorating health and would withhold their personal responses as a 'husband' or 'son' to the update just delivered. Beach (2002a) argued that the use of this technical language enabled the participants to talk about a highly sensitive/emotional topic because it focussed the discussion on the disease and practical aspects about what to do next rather than how each participant was feeling emotionally (which would have likely distracted the participants from the news update) (see also Jefferson 1980 on 'troubles resistance', and Maynard 2003 on 'stoicism'). The use of impersonal language was also identified as a practice doctors used during AIDs counselling sessions when asking patients to consider 'dreaded possibilities' about their future such as that they may go on to develop AIDs and come to a point when they are too ill to look after themselves properly (Silverman & Peräkylä, 1990). The authors argued that impersonal statements such as "*probably more than fifty percent of people go on to develop some sort of symptoms and some go on to develop AIDS*", is a less direct approach for asking patients to consider their future because it focuses on patients *generally* rather than the individual in the consultation (Peräkylä, 1993, 1995; Silverman, 1997; Silverman & Peräkylä, 1990). Doctors also asked patients to consider their future by using hypothetical or imagined scenarios (Peräkylä, 1993; 1995). Both of these practices created distance between the patient and the future uncertainty being

discussed, thus enabling the participants to address these delicate topics and, importantly, to document the patient's wishes before they were too ill to make informed decisions of their own.

Another resource used by medical professionals to discuss a patient's future is the use of implicit or euphemistic language. Luftey and Maynard (1998) examined a series of discussions with an oncologist and his patients as he informed them that their cancer was no longer treatable and that they were going to die in the near future. The authors found that this news was delivered in a caveated form, sometimes using "litotes" (Bergmann, 1992) such as "*I think it might be a good idea not to press on with the chemotherapy treatment*" (pp. 330-1), rather than addressing the patients' descent into palliative care with more explicit talk about death and dying. This finding was consistent with work by Rodriquez *et al.* (2007) who found that oncologists frequently talked about death using euphemisms (e.g. *pushing up daisies*) rather than an unequivocal vocabulary. This language has a similar function to the impersonal language described above as it is a way for the participants to talk about the patient's future in a more neutral manner; a manner that, if too direct, could result in the patient/caregiver becoming upset and preventing the conversation from taking place (Beach, 2002a). Rodriquez *et al.* (2007) also note that while implicit language may facilitate such discussions, it may also cause confusion about what the doctor is referring to. Patient understandings should thus be checked to ensure they know they are moving into the final stages of their illness (*ibid*).

Finally, conversations about a patient's future may involve optimistic projections to encourage those affected by the diagnosis to maintain hopefulness about their situation. Again drawing upon family telephone calls, Beach and Good (2004) found that in the later stages of the patient's illness, family members would often refer to upcoming tests and appointments as a way to remain optimistic about the future. The authors argued that such projections: "...move forward in hope that the future may hold better rather than worse 'news', possibilities that only a cancer expert might elucidate" (*ibid*, p. 14). In terms of optimism during oncology consultations, Leydon (2008) identified a "pairing phenomena" that involved physicians pairing the delivery of bad or uncertain news with information that was more positive or, at least, better in

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comparison such as: “*it’s potentially serious but the majority of these are cured*” (ibid, p. 1084). Rodriquez *et al.* (2008) similarly found that doctors conveyed prognostic information in ways that highlighted positive aspects of the news, 50% chance of surviving while downplaying negative connotations (e.g. *50% chance of dying*). Although optimism may facilitate discussions about the future between family members (Beach and Good, 2004), Leydon (2008) and Rodriquez *et al.* (2007) warn that such projections may reduce opportunities for patients to fully discuss the implications of their prognoses.

5.2.3 Summary

In this review I pointed to the communicative difficulties associated with discussing the patient’s future in various healthcare settings. The challenges related to many factors including varying preferences for this information, the difficulty of determining proximal outcomes for cancer, and the lack of clinical guidance about how to facilitate such discussions (Kaplowitz *et al.*, 1999; Butow *et al.*, 2002; Clayton, Butow & Tattersall, 2005; Hagerty 2005b; Parker *et al.*, 2007; Kaplowitz, Campo & Chiu, 2009; Almack *et al.*, 2012; van Vilet *et al.*, 2013; Walczak *et al.*, 2013; Cartwright *et al.*, 2014; Johnson *et al.*, 2015). These conversations have been labelled as ‘difficult future topics’ (Parry, Land & Seymour, 2014) by many researchers that have examined real-time consultations based on the language used by medical professionals when talking about the patient’s future (Silverman & Peräkylä, 1990; Bergmann, 1992; Peräkylä, 1993,1995; Silverman, 1997; Freese & Maynard, 1998; Luftey & Maynard, 1998; Maynard, 2003; Beach & Good, 2004; Rodriquez *et al.*, 2007; Leydon, 2008; Rodriguez *et al.*, 2008; Beach & Dozier, 2015; Maynard, Cortez & Campbell, 2016; Pino *et al.*, in submission).

Findings about prognostic discussions specifically have typically been drawn from self-reported data rather than actual consultations; and the relevant CA studies described above have all focussed on doctor-patient interactions rather than interactions with other healthcare professionals or other people affected by the disease (such as caregivers). A recent review by Johnson *et al.* (2015) argued that more research needed to examine the views and behaviours of different professionals involved in cancer care, especially specialist nurses who are intricately involved in providing patients with information and support (ibid, p. 566). There is some evidence to suggest that prognosis requests are

problematic for Macmillan call-handlers, shown here in the following quote from a qualitative interview that asked nurses about challenging aspects of their role:

*“One example I have is a woman who **er wanted me to give her a hypothetical prognosis but we deal in facts and information and when I wouldn’t do that she swore and hung the phone up on me...**”*
(CTN023) (Ekberg *et al.*, 2014¹⁴).

In this chapter I will examine how requests for a prognosis were formulated on the helpline as well as the interactional resources used by nurses to respond. Findings from this research will contribute to an understanding about how prognosis discussions actually unfold and how call-handlers managed such requests on a helpline (rather than face-to-face as with the previous research). In the next section I will describe the sample of calls used for this analysis.

5.3 Uncertain Future Matters: Prognosis Requests and their Management

5.3.1 Sample Description

A significant proportion of callers (41%) telephoned the helpline for information about uncertain future matters including illness progression, cancer recurrence, end of life, and prognosis requests (see Chapter 3). Table 12 provides an overview of the calls in which a prognosis was specifically requested (n=11).

Table 12: Sample description of callers requesting a prognosis.

No.	I.D.	Caller	Medical History
1	PAT 17 Nurse7	Female patient	Secondary liver cancer. Had major surgery for bowel cancer last year.
2	PAT 31 Nurse9	Female patient	Oral cancer called Mucopidermoid

¹⁴ This quote comes from a call-handler during these interviews but this particular excerpt was not produced in the article cited.

			Diagnosed yesterday.
3	PAT 37 Nurse10	Female patient	Endometrial cancer. Has had a hysterectomy and she is due to see a consultant again soon.
4	PAT 45 Nurse5	Female patient	Secondary lung and liver cancer (she had breast cancer 14 years ago). Due to start chemotherapy.
5	PAT 50 Nurse4	Male patient	Thyroid cancer and tonsil cancer. Scheduled for operation and radiotherapy.
6	REL 2 Nurse12	Daughter of a female patient	Lung cancer. Has had her lungs drained and uses a nebuliser three times a day.
7	REL14 Nurse11	Sister of a female patient	Mesothelioma. Undergoing chemotherapy.
8	REL 16 Nurse16	Partner of a male patient	Terminal lung cancer. Undergoing radiotherapy.
9	REL 25 Nurse8	Daughter of a female patient	Secondary brain tumour (primary cancer is a malignant melanoma). The patient has had an operation and is due to start radiotherapy soon.
10	REL 38 Nurse10	Sister of a female patient	Breast cancer. The patient has had a lumpectomy.
11	REL 46 Nurse8	Daughter of a male patient	Stage 4 bowel cancer. The patient was diagnosed the day this call was placed and is scheduled for a PET scan.

The collection is split relatively evenly between patient and caregivers, most callers enquired about patients with newly diagnosed cancers, and most patients were in receipt of curative treatment at the time of calling. The reasons to focus on prognosis requests and responses is based on the arguments described above in relation to the existing literature but also on how these sequences unfolded: they were often long and complex and required detailed examination of extensive excerpts to understand what was going on (this will become evident when we examine nurse responses in section 5.3.3). Furthermore, although such requests may be under-represented

in this corpus¹⁵ they posed difficulties for the nurses taking the calls and so warranted in-depth examination.

In the next section I will describe how callers requested a prognosis.

5.3.2 Requesting a Prognosis

Callers requested a prognosis in one of two ways using either a direct or an implicit turn design, but direct formats were more frequent. Callers typically used the word ‘prognosis’ or language associated with prognoses such as ‘life expectancy’ and ‘length of life’, which established a discussion of a timeframe as the relevant next action. Most callers orientated to the contingencies surrounding their requests being granted and solicited general prognoses rather than forecasts for individual patients.

The caller in extract 5.1, for example, a daughter who enquired about her father’s lung cancer, was concerned that he has not understood the implications of his diagnosis, and so his prognosis, because the meaning of palliative treatment was not explained to him during a recent consultation (i.e. that it alleviates pain and reduces symptom burden rather than actively curing the disease). After explaining this dilemma to a nurse (lines 1-15), she formulated a request for his prognosis.

Extract 5.1

MCREL46/Nurse8, Carer request for a prognosis, [03:39-04:08].

- 1 C: ...And so (.) u:::m, .tck mum walked out thinking it was
 2 goo::d .H[HH because (.) ob]viously its quite clever the
 3 N: [Mm hm, mm hm,]
 4 C: the way they do i:t?=they gi:ve you lots of good news and I
 5 was focusing on that and not really taking in the: ne:xt
 6 bi::t
 7 N: Mm[:::,
 8 C: [And you’re- we’re in and ou:t within five minu:tes.
 9 N: Mm hm, u[m hm,
 10 C: [U:::m (0.6) bu[t I](.) I don’t know (0.3) .pt if
-

¹⁵ Although this is hard to determine based on the codes used by Macmillan to categorise caller’ reasons for calling. This was discussed in chapter 3, see pp. 57-8.

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11 N: [.tck]
12 C: I should tell hi::m? (.) and #°I°# w[hat's] the point in
13 N: [↓Mm:,]
14 C: telling hi::m if he doesn't (.) >we don't< know (.) what
15 the PET scan is going to show yet,
16 N: Mm hm, mm hm,
17 C: And [what i]s the li:fe expectancy (.) of something like
18 N: [°Sure°]
19 C: that.
20 (0.4)

The request (lines 17-18) was designed to solicit an estimate about how long the patient would likely to live with this cancer type and this was accomplished with the use of “life expectancy”. Note that the caller did not ask about her father specifically and instead requested a prognosis for “something like that” (i.e. stage four lung cancer), a request which asked for general information about his cancer type.

This pattern of requesting general prognoses using a direct turn design was the most frequent practice used to solicit prognostic information within the helpline calls analysed. The caller in the next extract, a daughter who called on behalf of her mother, similarly requested a prognosis for ‘lung cancer’ rather than the individual patient. This request occurred towards the end of her problem presentation to a nurse.

Extract 5.2

MCREL2/Nurse12, Carer request for a prognosis, [0:13-01:31].

1 C: ...↑E::m and (.) I just wanting to find out a bit more:
2 information. >I know that< she's had her (.) <lungs drained
3 twi:ce. .hh And that she has a nebuliser three times a
4 da:y. .hh .pt And that u:m (.) I:: think that they probably
5 suspect that they'll have to drain her lun:gs from em
6 fluid. .hh Probably once every two months.
7 N: (Oh rea[:lly])
8 C: [.hhh I: was just wondering what the prognosis with
9 lung cancer is.= Is- is- (.) you know for how long: (.) d:o
10 you have to live with it or how long do you (.) have left
11 to live or .hh[h em w]hat [you]know w::- ↑U::m (.)I: I=

12 N: [↑Mm:.,] [↑Mm:]
 13 C: =just want to double check that they're doing everything
 14 they ca::n do for her, .h[hh] >coz I'm gonna try< and go=
 15 N: [Mm,]
 16 C: =see her as soon as as possible.

The caller requested a general timeline from the nurse by using the word “prognosis” and she solicited information about lung cancer rather than her mother specifically (lines 8-9). The use of impersonal language continued in the expansion of this request, “for how long: (.) d:o you have to live with it” and “or how long do you (.) have left to live or”, which created distance between the requested information and the patient. This caller also added an account about why she was soliciting this information (lines 12-16), indicating that although she formulated her request using impersonal language, she was nevertheless seeking a prognosis for her mother.

Earlier in the call from which this next extract was taken (5.3), the caller, a female patient with endometrial cancer, asked the nurse to explain the meaning of ‘stage’ and ‘grade’ and used the nurse’s responses to ask about whether a cancer could be contained in the womb (i.e. a low stage) but also be classified as aggressive (i.e. a high grade). The nurse emphasised that the most important aspects of treating cancer was removing the cancerous cells and ensuring the cancer had not spread anywhere else in the body. The caller then asked the nurse a hypothetical question about her prognosis.

Extract 5.3

MCPAT37/Nurse10, Patient request for a prognosis, [05:11-05:29].

1 C: Ri:ght.(0.2) Oka:y. .hhh And if (.) #I::# I I know this is
 2 ↑hypothetical but I feel (>a bit<)it's jus- this is s(h)o
 3 helpful £thank you£ .hhh
 4 N: °Ah hah°
 5 C: U:::m is if it's (.) gra::de (.) if it's a more aggressive
 6 form of cancer but it's stage o:ne and it's been
 7 remo:::ved,(0.2) .hhh does that: (.) have (0.4)
 8 consequences fo:r (.) your prognosis.

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At line 1 the caller self-repaired from immediately soliciting this information to a preface that provided more context to her question (“And if (.) #!:# I I know this is ↑hypothetical but...”) (lines 1-3). The research literature shows that participants often preface requests when they are trying to minimise a dispreferred action type from their interlocutor such as a rejection or refusal (Schegloff, 2007). The preface used by the caller was slightly different as she did not ask the nurse for permission to formulate her request (e.g. *can I ask you a question about prognoses*), where the answer may have inhibited the caller from soliciting this information; and instead used it to frame her question as an imagined scenario. This framing, along with the impersonal language used to formulate her request (“does that: (.) have (0.4) consequences fo:r (.) your prognosis”, lines 7-8) distanced the patient from the question posed, as it is related to patients generally rather than her particular situation.

The callers so far all formulated their requests in a direct manner, ones that clearly projected an estimated timeline as the relevant next action. The callers in the final two extracts formulated their requests more implicitly when compared to the cases examined so far. The caller in extract 5.4, for example, a female patient with a rare oral cancer called “Mucopidermoid”, used tagged utterances to embed her prognosis request within other requests for information.

Extract 5.4

MCPAT31/Nurse9, Patient request for a prognosis, [01:18-01:31].

- 1 C: ...but (0.2) I just can't find any informa:tion on it
2 ju'kno::w (0.3) is it[a dang]erous cancer o::r,
3 N: [°°yea°°]
4 (0.4)
5 C: you know things like tha::t.
6 (0.3)
7 N: Yeah. Yea[h].
8 C: [And] what like (.) progno:sis is and thi:ngs.

Transcription Note

- Line 2 – Her pronunciation of ‘you know’.

The patient formulated her request in stepwise fashion, one that started with her explanation about not being able to find “any information” about her cancer type to the type of information she required: “is it[a da]ngerous cancer o::r,” (line 2). Although there has not been a lot of conversation analytic work about the tagged particle ‘or’, a doctoral thesis by Drake (2013; see also Lindström, 1997) showed that the utterance functions multifariously, including managing aspects of preference organisation such as the presuppositions indexed within requests for information. In terms of the caller here, the particle ‘or’ neutralized the preference for a confirming or disconfirming answer to her request making both responses unproblematic (i.e. if the nurse went on to confirm it is dangerous) (a similar finding was proposed by Stokoe 2010 about the design of ‘delicate’ questions during speed dating). The subsequent increment (Ford, Fox & Thompson, 2002), “you know things like tha::t.” (line 5), produced because the nurse did not begin his turn at this point, broadened her request so other pieces of information about the dangerous side of her cancer were also relevant next (without the caller having to specify what they might be). It is only after the nurse did not begin his turn again (line 6) that the caller formulated a similarly hedged request for general prognostic information, “And] what like (.) progno:sis is and thi:ngs.” (line 8).

Finally, the caller in extract 5.5, a partner that enquired about the patient’s recent diagnosis of terminal cancer, formulated her request in a similarly hedged form.

Extract 5.5

MCREL16/Nurse16, Carer request for a prognosis, [03:40-04:15].

- 1 C: But I don't know: (0.6) what we're lookin' at in
 2 t[erms: °of-°] (0.3) of #e::# what to expect or:=it's
 3 N: [(°Mm hm, °)]
 4 C: the:- the ca:ncer in his ch- uh lungs is inoperable.
 5 (0.5)
 6 C: .HHHHHH S[o::]: am I: to take that it's quite
 7 N: [Mn,]
 8 C: badly::: (.) adva:::nced or::: (0.2) .hh u:::m it's just in
 9 the wrong pla:ce or:::=I mean I just don't know::: (.) the
 10 right questions to a:sk or: or or what- or what I'm: to
 11 expec:t on on: .hhh management an:d length of: (0.4) li:fe

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12 or anything. I just don't know what to say to these people
13 to find out.

Transcription Notes

- Line 3 - Very hard to hear but there are two syllables and the first one has an "m" sound".
- Line 5 - I put the silence as a gap because the had caller finished her previous turn with downward intonation so the nurse could have produced a minimal acknowledgement in this position. Her delayed minimal acknowledgement at line 7 shows her own orientation to the relevancy of such a token during this sequence.

The caller first oriented to a future topic with: "But I don't know: (0.6) what we're lookin' at in t[erms: ° of-° (0.3) of #e::# what to expect or" (lines 1-2), an opaque formulation that could be understood in various ways (i.e. about treatments, symptoms, support available, and so on). It is perhaps due to these various understandings that the caller became more specific about the information she was looking for, starting first with whether his cancer was inoperable (line 4), badly advanced (line 8) and if it is in the wrong place (line 9). Most of these utterances were tagged with the particle 'or' which again neutralized the preference organisation of this request, rendering a confirming or disconfirming answer unproblematic (Lindström, 1997; Drake, 2013; Stokoe, 2010). The prognosis request was embedded near the end of this presentation and similarly solicited general information like the callers in the previous extracts: "what I'm: to expect: t on on: .hhh management an:d length of: (0.4) ↑li:fe or anything" (lines 11-12).

In summary, caller requests for a prognosis were typically produced directly, using language associated with estimated timelines (such as prognosis, life expectancy, and length of life). Even in the cases where the request was produced less directly (implicitly), the callers still used language associated with 'prognosis' but they embedded their request in other requests for information. A pattern across all of these requests was the use of impersonal language - so rather than asking "*what is my prognosis*" or "*what is my mother's life expectancy*", the callers all solicited information about cancers types or patient survival in general. This finding is consistent with previous research that has shown people commonly frame sensitive discussions in this way because it creates distance between the requested information and the patient personally involved (thus enabling the participant to talk about a highly sensitive matter in a less emotive way) (Beach, 2002a; Silverman & Peräkylä,

1990; Peräkylä 1993, 1995). By speaking in general terms, the callers also displayed their awareness of what information the nurses were able and not able to provide over the telephone. It was thus a way the callers aligned with the services on offer from the helpline, providing the nurses with opportunities to discuss this matter in a similar way.

However, although the callers used impersonal language to request general prognoses, they were nonetheless talking about their or the patient's personal situation. It was the nurses' subsequent focus on the individual rather than the general that often resulted in interactional trouble during these sequences (e.g. conflicting pieces of information/advice, misalignments between the participants, repetition, and so on), a matter I will discuss in the next section.

5.3.3 Nurse Responses to Prognosis Requests

Earlier (section 5.2.3, p. 107) I quoted a call-handler who described an occasion when a caller became angry because she did not provide her with a 'hypothetical prognosis'. According to the nurse, prognosis requests are problematic because the helpline "deal[s] in facts and information" rather than uncertainties about the patient's future. Sometimes, in response to such requests, nurses highlighted the remit of their expertise and informed callers that they were possibly unable to provide them with the information they were looking for, as illustrated in the following excerpts.

1. "So it's all lo::cal. Okay. Alri:ght. .hhh I'll have ↑little loo::k. I mean I I I think it's going to be pretty ha:::rd #er# t- to get an an definitive ans:wer on thi::s .hh because everybody's so different."
2. "Ri:ght. Oka:y. .hhhh Erm: (.) Well without knowing a little bit more information it's rea:lly difficult for me to say: which (.) I:: >suspect< you might have (.) know(h)n."
3. "It's .HHH very very difficult >I mean< I wouldn't li:ke to say for your: particular situation 'cause I think you'd need to probably talk to your consultant about tha:::t."
4. "HHH We:::ll >y- y-< you kno:w it's very it's very difficult to give a prognosis for fo::r fo::r for someone becau:::se .hhh it depends on the:: it depends- if if they have treatment .hh it depe::nds on the benefit that people get from treatment."
5. "And they: probably won't be able to be terribly precise .h because .hhh u::m it's quite har:d to be so.."

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Through these various turn designs, the nurses indicated that they might not be able to estimate the patient's prognosis or answer the caller's prognosis-related question. Such turns may be viewed as ways to manage caller expectations in terms of what they can and cannot provide over the telephone as a call handler. However, as my analysis will show, nurses often produced such turns and then proceeded to discuss the patient's prognosis and this frequently led to interactional difficulty.

Before examining the difficulties associated with discussing the patients' prognosis, I will examine a call that differed from others in this collection as the nurse responded to the request with helpline-appropriate information and advice about prognoses. This caller, a female patient with an oral cancer called "Mucopidermoid", told the nurse that she was unable to find "much information" about her type of cancer including whether it was dangerous and its (her) prognosis (lines 1-4) (the request was analysed on p. 113). The turns relating specifically to the nurse's engagement with the prognosis talk are numbered on the transcript and these will correspond with the 'steps' described in my subsequent analysis.

Extract 5.6

MCPAT31/Nurse9, Nurse response to caller request for a prognosis (minimal difficulty), [01:32-04:08].

1 C: ...but (0.2) I just can't find any informa:tion on it
2 ju'kno::w (0.3) is it[a da]ngerous cancer o::r, (0.4)
3 N: [°yea°]
4 C: you know things like tha::t.
5 (0.3)
6 N: Yeah. Yea[h].
7 C: [And what like (.) progno:sis is and thi:ngs.
8 N: .hhhh U:::m .tckhhh #e:# I mean there's quite a bit on it
9 >I if< you're looking fo::r wri- don't have a booklet on it
10 as su:ch becau::se .hh our main booklet on (.) the
11 treatment o::f (.) cancers >in the head and neck< .hh is
12 just about understanding head and neck cancers .hh in in
13 general. (.) .hh U[:::m] (.) this is a commonest ty::pe
14 C: [Ri:ght.]
15 N: the::: #eh# of: .hhh (.) salivary gland tumour that there
16 i::s okay?="

- 17 C: =Ri:gh[t.
 18 N: [U::m and sometimes they wi::ll, (0.2) .hh >it's the
 19 most common salivary gland tumour< and it it (.) affects
 20 people mainly (0.5) .tckhh e::r f- between the ages of
 21 twenty and fifty.
 22 (0.3)
 23 C: Right.
 24 (0.2)
 25 N: **1-->** O::kay, .hh u::m now your doctor (0.5) >when you're asking
 26 about< prognosis you need to ask him when you go ba::ck
 27 .hhh what grade it is. (.) >I d[on't] know if< they've
 28 C: [Yeah]
 29 N: told you anything about it. .hh Because if you've been
 30 looking at information .hh you'll probably:: have picked up
 31 the idea .hh that there are different grades of cancer.
 32 C: Yea:h
 33 (.)
 34 N: .hh Oka::y >so they-< the grading .tck is important y- y-
 35 i:t would be scored one two or three:: (.) .hh so that's
 36 from low grade, (.) through to number three which is the
 37 highest. .hhh [(An-)] And someti::mes depending on the
 38 C: [Right]
 39 N: grade .hhh what they might need to do is follow up with
 40 some radiotherapy.
 41 (0.2)
 42 C: Right.
 43 N: .pt Oka::y .hhh
 44 C: Yeah
 45 N: surgically it's been removed, .hh u::m the si::ze and the
 46 sta::ge .hh of the tumour is something that they'll-
 47 they'll work out as well.
 48 (0.4)
 49 C: Ri:ght.
 50 N: **2-->** .hhh Okay n::ow (.) .HH when we're talking abou:::t (0.2)
 51 .HH how can I put it y- prognosi- you mentioned the word
 52 prognosis. .hhh A[nd] er you reali::ze maybe that
 53 C: [Yeah]
 54 N: docto::rs .hhh don't talk about cure rates they kind of
 55 work backwards .hh which can be [>a bit<] pessimistic
 56 C: [°Right°]
 57 N: for members of the public. .hh But they w- are- I'll

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58 explain the rationale. .hh There's a te::rm, (0.2).tck
59 kno:wn as five year survival rate (0.3) .HH oka::y and
60 people pa[nic] when they hear that because >they think<
61 C: [Yea]
62 N: .hhh oh my go::d (.) that means I've only got five years or
63 something like tha'. .hh I[t do]esn't mean that at a:ll it
64 C: [Yeah]
65 N: it jus means that with cancer, .hh [e:r](.) a useful way
66 C: [Yeah]
67 N: to measure (.) .hh how successful >treatment is< and how
68 well people are likely do:: .hh an how- or how aggressive a
69 cancer might be: .hh is to look at for every hundred people
70 (0.5).tck diagno::sed with certain type of cancer .hh how
71 many, (0.3) are alive and well and cancer free:: (.) five
72 years down the line from a biagnosis.
73 C: Ri:ght.
74 N: 3--> .tck Oka::y?.hh Now (.) I don't know if you've found
75 anythin' on tha:t .hh f:or the mucol (.) epidermoid
76 carcinoma that you've been diagnosed with. (.) .pt Have you
77 found anything at all.

Transcription note

- Line 72 - He does actually say “biagnosis” rather than “diagnosis” and this remains unrepaired.

The caller's request sought both general and specific information about her cancer type which the nurse handled separately and in that order. The nurse displayed *some* difficulty in starting his turn with the in-breath, “U::m”, lip smack “.tckhhh” and repair “>I if<” (line 8) but he soon recovered and moved on to provide general information about the patient's cancer type¹⁶ (arrow 1). This included a confirmation that there was a lot of information available (line 8), that the patient had the most common type of salivary gland tumour (lines 13-15), and that her cancer generally affected people between the ages of twenty to fifty (lines 19-21). The nurse abandoned a turn at line at 18, “U::m and sometimes they wi::ll, (0.2)”, which could have been completed with information about treatment based on his reference (“they will”) to the patient's medical team with (a common way nurses refer to the healthcare

¹⁶ This turbulence may be related to the call-handler first stating that there is “quite a bit” of information available (line 8) but then noting that Macmillan only had a general booklet about understanding head and neck cancers rather than a specific book about her cancer type (lines 9-13).

professionals involved in a patient's care). This was replaced with the other forms of general information listed above because: a) the patient already informed the nurse she had only had surgery so far, and b) the nurse needed to know whether the patient's cancer had been staged and graded before he could surmise what further treatments her medical team might suggest (this occurred next). The nurse then addressed the caller's prognosis request.

Step 1: Advice to speak with the patient's doctor - The nurse addressed the two interrelated pieces of information requested by the caller about whether her cancer is dangerous and its prognosis¹⁷. He was clear from the beginning of his turn that the patient needed to return to her doctor to find out more information about her cancer, specifically its grade. Rather than just advising the caller to speak with her doctor, though, he explained the different ways cancers are scored (lines 34-37) and why this was important in relation to further treatment the caller may have in the future (lines 37 - 47) - information she could use in her next consultation.

Step 2: Addressing the prognosis talk (with information about prognosis-related matters) - At lines 50-52, the nurse moved on to the third element of the request about the prognosis for this type of cancer: "Okay now (.) .HH when we're talking abou:::t (0.2) .HH how can I put it y- prognosi- you mentioned the word prognosis." The caller's use of the word "prognosis" was problematised through this construction which projected that the nurse was not going to use this word in the subsequent discussion, or that he was going to talk about prognoses differently to the caller's current understanding. This is consistent with the information he delivered next as he explained that prognoses are not determined using "cure rates" (lines 54-5) but by how successful treatment is five years after the original diagnosis (lines 58-72). The nurse empathised with how this may come across to patients who want information about their prognoses, ".HH oka::y and people pa[nic] when they hear that because >they think< .hhh oh my go::d (.) that means I've only got five years or something like tha'. .hh I[t do]esn't mean that at a:ll it it jus means..." (lines 59-63), and thus acknowledged the anxiety patients may

¹⁷ They are interlinked because doctors determine how dangerous a cancer is by grading it and this score is used as one factor to determine a patient's prognosis.

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experience when considering uncertain future matters (but he did not go further and provide a timeframe for her particular cancer type).

Step 3: Sequence closure (checks understanding) - The sequence is brought to a close by the nurse who asked the caller if she was able to find specific information about her cancer type (the information so far was about grading and prognoses generally rather than how these factors applied to her specific form of cancer) (lines 74-77). The caller said she looked online but did not understand the medical terminology and the nurse further explained how cancers are graded in relation to disease progression (data not shown).

The key observations to note about this extract are 1) the nurse displayed little orientation to difficulty when discussing this uncertain future matter but still addressed all aspects of the callers request about whether her cancer was dangerous and its prognosis; 2) the nurse constructed the request as a doctorable problem early on in the sequence (line 25) but rather than just recommending the caller speak with her doctor, he advised the caller on what to ask and why this was relevant in terms of the information she needed. This was important because it told the caller that he as a call-handler could not provide all of the answers she wanted but, in the meantime, before her doctor visit, could provide some information; and 3) the nurse checked the caller's understanding throughout with his use of "okay" (lines 25, 34, 43, 50, 74) to confirm they were talking about this matter together and that the caller understood his medical terminology (the caller displayed this with her active acknowledgement tokens, "yeah" and "right", throughout). To summarise, the nurse provided constructive information about an uncertain future matter *without actually providing a specific prognosis*.

5.3.4 Nurse Orientations to a Difficult Future Topic

The next calls to be considered contrasted significantly with the first example as the nurses all displayed an orientation to difficulty in discussing this uncertain future matter. This was evident in the content of the prognosis discussion which, unlike the nurse in extract 5.6, focused on the challenges they and other medical professionals have in providing such estimates rather than talking about other relevant information about prognoses (such as the five-year survival rate). The following are examples of how these discussions

typically unfolded. I will show that it was the nurses who tried to provide a prognosis or answer a prognosis-related question who encountered the most difficulties; as did the nurses who did not construct the problem as one for the patient's doctor early in the interaction.

The caller in extract 5.7 is a male patient who was diagnosed with two separate cancers in his throat. This sequence comes from the problem presentation phase of the nurse call, shortly after he provided a succinct medical history. The nurse asked two medically-related questions about his cancer (lines 3-9) before responding to his request.

Extract 5.7

MCPAT50/Nurse4, Nurse response to caller request for a prognosis (orientation to a difficult future topic)., [0:42-12:38].

- 1 C: I was wondering what the er (.) prognosis is for er this
 2 e- this type of er cancer
- 3 N: .HH Ri:ght. Okay. So .hh it's, (.) it's do you know where
 4 it's actually begu::n (.) has it begun in the ↓thyroi::d.
 5 C: It's begun in me er: tonsils.
- 6 N: In the tonsi:l. [.HHH A]nd have you got any ide:a of of=
 7 C: [Yea:h.]
 8 N: =what ty::pe.=>Have they given you< the na::me of it at
 9 a::ll,
 10 (0.2)
- 11 C: E::r they 'aven't no[:: .]
 12 N: [.tck]
 13 (0.5)
- 14 N: 1--> 'kay, oka::y. .hhh Wul let me just have a little look. (i
 15 I'm-) I don't know if I'm going to be able to give you any
 16 >clear answers on this< but what I might be able to do is
 17 give you a few more questions to a:::sk .hhhh from your
 18 consultant u::m,
 19 C: °Mm°
- 20 N: U::m >th- that< might then help help us >sort of< find
 21 out a little bit mor:e of an answer to this. [.HH 'cause=
 22 C: [↓Yea::h
 23 N: =it's often you need a lot of information first of
 24 a:::ll .hhh <e:::rm (.) to::: > (.) erm .tckhhh (0.3)
 25 to know exactly what the sit- >'cause each situation's<

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26 quite individual and and and you have to know a fe[w=]
27 C: [Ye:s.]
28 N: =things (alob-) about it be[fore you know-]
29 C: [The main cance::r] the main
30 cancer now (now is in) the thy- thyroi::d.
31 (0.4)
32 N: Yea::h. But it's the tonsil where it started is i::t?

(52 lines omitted re the nurse asking the caller a series of questions about his cancer including if the doctors mentioned a stage (his tonsil is stage one and thyroid stage 2), if the caller has two separate cancers (caller confirms he does), what specific type of thyroid cancer it is (papillary), if the treatment has been prescribed for his thyroid or tonsil (caller thinks it is both) and whether the cancer has spread to elsewhere in his body (caller says it has not)).
33 N: **2-->** So it's all lo::cal. Okay. Alri:ght. .hhh I'll have ↑little
34 loo::k. I mean I I I think it's going to be pretty ha::rd
35 °er° t- to get an an definitive ans:wer on thi::s .hh
36 because everybody's so different and you're quite a unique
37 case to have two separate cancers very close together.
38 C: [°Ri::ght°
39 N: [.hhh but what it <sou::nds to me::: like> .hh is >that
40 the::y're< the treatment >they're giving you< i:s pretty
41 radical it's quite a l::ot of treatment. .hh So what
42 they're probably aiming for is to in in the hope that
43 they'll get rid of it for you[::] .hh U::m .hh but=
44 C: [Mm:,]
45 N: =(.) but it oft- it isn't often after until you've had the
46 treatment and they scan you to see::: .hhh u::m to be
47 su::re that they've got rid of it all that they've got a
48 better idea of what the outlook is to be hones[t with you:.
49 C: [Ri::ght.]
50 N: .hhh u::m so it might be too early >kind of< to kno::w.
51 .hh ((sniff)) e::r >but le-< bear wi- bea:r with me a
52 minute >I'm just gonna< pop you on hold and just have a
53 little rea:d for you::...

(The caller is put on hold for 4 minutes. The nurse comes back and confirms the name of his cancer is called "papillary" before providing information)).
54 N: **3-->** .hhhhh (.) .tck well i- I mean for papillary:: it's a very
55 very good prognosis on the who:::le.

56 C: Ri:ght,
57 N: .tck U:::::m (.) so::::: (.) e:::::r (0.8) #i:::#
58 yea:::::h. (1.2) u:::m (0.7) yea:h. >I mean< it's it's
59 it's .HHH very very difficult >I mean< I wouldn't li:ke to
60 say for your: particular situation 'cause I think you'd
61 need to probably talk to your consultant about tha:::t.
62 .hh[hh you] know >because< they'll be able to tell you (as)
63 C: [Ri:ght]
64 N: mu:ch mo:::re=they'll have access to your sca:::ns and
65 they'll be able to >sort of say< in your individual
66 situation .hhh but it- I mean it's a very- it does
67 respo:::nd er:::m >you know< surgery being the >kind of< the
68 mai:::n .hh u:::m thi- th e- fa:::cto:::r. .hh er:[m]
69 C: [°°ye°°]
70 N: (0.3) .tck so::: u:m I don't know:, have you (i- i-) have
71 you got a family history of this at a:::ll? Do you kno:::w?

((9 lines omitted re the caller saying he does not have a
family history and the nurse asking the caller's age))
72 N: 4--> .hhh I mean (0.3) .tck nor- normally you know #i:::t# it's:
73 (0.2) ↑i:::f e:::::r >you know you've got a< history of it
74 in your family .hh that can sort of make the::: >you know:<
75 (0.2) then it's sometimes it's it's harder. .hh Sometimes
76 people don't do ↑quite as well as those who have:::n't. .HHH
77 U:::::m it very much depends::: I think on once they've done
78 the surgery once they find out exactly how much of the
79 local area is affe- is affected and I'm just talking about
80 thyroidal cancer at the moment. .h[hhh (.)] U:::m and how m-
81 C: [Ri:::ght]
82 N: how (.) ho:w off- (0.4) optimisitic they feel that they ha-
83 that they've managed to get rid of it a:::ll. .hh u:m
84 (.) .tck and then >sort of< ho:::w how well it >sort of<
85 depen- it u:::m .tckhhh how well it responds to:::
86 treatment. .hhh u:::m] so::::: .hh u:::m (0.3) bu:::t
87 C: [°°Ye°°]
88 N: (0.2) e °oh:::° I'm just trying to::: (.) hang on a minute
89 .hh (0.6) e:::r I'm just trying to double check what,
90 (0.3) .tck her:::e we go hold on a second. (2.2) .HH (0.5)
91 .tck yea:::::h I mean it wull a:lso (0.5) u:::m (0.6) th- y
92 one thing to a:sk is whether they think it's a s: slo:w
93 growi:::ng (.) or no:t. .hh u:::m (.) a:::nd >whether it's

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94 kind of< gone outside of the thyroi::d capsule .hhh and
95 obviously that will i- will you know is gonna effect .hh
96 >sort of< how (.) ho::w (0.3) easy it is for them to
97 trea::t.
98 C: R[i::ght
99 N: [You know u:::m .hhh and the:::n .h u::m (.) >I'm just
100 trying to see sort of< how we:ll: (0.2) the::: .hh
101 radiotherapy is actually quite (.) you know is quite well
102 (.) wi:dely u:::sed and is generally very (0.6) effective
103 for these types of cance::rs. .HH[H]U::m so it's just
104 C: [(Mm)]
105 N: rea::lly (.) finding out a::fterwards, (0.2) .tck exactly
106 how well they think it's responded. .hh but generally:: you
107 know the response and the results of the treatment are
108 a::re a:re pretty ↑goo::d. .hhh U::m (.) now the tonsi::l
109 side of thi::ngs...

Transcription notes

- Line 82 - 'off- 'sounds like it could have been the start of "often".
- Line 88 - the °oh::° sounds like a "sighy" oh.

Step 1: Managing the caller's expectations – The nurse's first turn projected that she was going to search for this information, either by looking in the resources Macmillan have in their office or by searching for it online: "Wul let me just have a little look." (line 14). She is clear, though, about the limits of expertise and informed the patient that she might only be able to advise him about prognosis-related questions to ask in a next consultation: "I don't know if I'm going to be able to give you any >clear answers on this< but what I might be able to do is give you a few more questions to a::sk .hhhh from your consultant u::m," (lines 15-18). The nurse accounted for her inability to answer by explaining that a lot of information about a patient's medical history is needed first before such timeframes can be determined based on the fact that each situation is "quite individual" (lines 20-28). This first part of the nurse's turn simultaneously constructed the problem as a doctorable one and managed the caller's expectations about the services the helpline could provide, thus preparing the caller for the type of general information he may receive during this call. However, in overlap with the nurse's turn (line 29), the patient provided more information about his cancer, "The main cance::r the main cancer now (now is in) the thy- thyroi::d." (lines 29-30), thus displaying his understanding of the nurse's previous account that she needed more

information about his cancer type and treatment – which he has – in order for his request to be granted. They then discussed the patient’s medical history in more detail (data not shown but see the summary in the transcript).

Step 2: Managing the caller’s expectations (with information) - After completion of this question series, the nurse produced a similarly designed preface to her upcoming information: “it’s all lo::cal. Okay. Alri:ght. .hhh I’ll have ↑little loo::k. I mean I I I think it’s going to be pretty ha:::rd °er° t- to get an an definitive ans:wer on thi::s .hh because everybody’s so different and you’re quite a unique case to have two separate cancers very close together.” (lines 33-37). She went on to provide information about the patient’s treatment and why it had been prescribed, and further managed the caller’s expectations by saying that it might be too early for him to receive information about his prognosis: “but it oft- it isn’t often after until you’ve had the treatment and they scan you to see::: .hhh u::m to be su::re that they’ve got rid of it all that they’ve got a better idea of what the outlook is to be hones[t with you::: .hhh u::m so it might be too early >kind of< to kno:::w.” (lines 45-50). It is here that the nurse put the caller on hold to search for more information online.

Step 3: Addressing the prognosis talk (with a prognosis) - Despite her numerous accounts about the challenges associated with providing a prognosis, she nevertheless engaged with the caller’s request and began to deliver a prognosis: “.hhhhh (.) .tck well i- I mean for papillary:: it’s a very very good prognosis on the who:::le.” (lines 54-5). It is after she articulated this good news that the nurse oriented to difficulty, and this was particularly evident in the amount of speech perturbation within the next part of her turn: “U:::m (.) so::: (.) e:::r (0.8) #i::# yea:::h. (1.2) u::m (0.7) yea:h.” (lines 57-8). She then backtracked on the information just provided, “>I mean< it’s it’s it’s .HHH very very difficult >I mean< I wouldn’t li:ke to say for your: particular situation” (lines 58-60), which was akin to her earlier information about each situation being “quite individual” (see lines 25-6). The nurse switched back to considering the prognosis, “but it- I mean it’s a very- it does respo::nd er::m >you know< surgery being the >kind of< the mai:::n .hh u::m thi- th e- fa::cto::r.” (lines 66-68) and repeated earlier information about surgery before she was explicit about her lack of knowledge, “.hh er:[m (0.3)

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.tck so:: u:m I don't know:," (line 68-70) and abandoned this information-giving to solicit more details about the patient's medical history (lines 70-71).

This repetition occurred throughout the rest of the sequence, and indeed the call, as the nurse continued to switch between providing a prognosis and explaining the difficulty in doing so. Note that the nurse did advise the caller about what to ask in a future appointment (lines 91-7). This is what she said she would provide before putting the caller on hold; but it did not have the same interactional effect compared to if it was placed in an earlier sequential environment. If placed earlier the nurse could have advised the caller on what to ask during a future consultation without putting the caller on hold and engaging further with the prognosis talk.

The nurse in the next example similarly attempted to answer a prognosis-related question and encountered trouble when doing so. This caller asked a question about her mother's prognosis and whether her life expectancy would be shorter if the medical team identified additional tumours to the existing one in her brain.

Extract 5.8

MCREL25/Nurse8, Nurse response to caller request for a prognosis (orientation to a difficult future topic), [09:01-10.57].

1 N: Ye:ah. Yep yep yep. >wi y-< >Cause as I say< I can ta:lk
2 very much in general ter:[ms]but um .HHH [(?)
3 C: [Yeah,] [As a general
4 C: ter::m,
5 N: ↓Ye::s yea[:h
6 C: [If you are[: (.) gi]ven a prognosis with (.)
7 N: [°°Yeah°°]
8 C: one brain tumour a[nd the]n they do another (0.2) sc:an
9 N: [Mm hm,]
10 C: a[nd fi:]nd ou:t (.) t[hat on]e's one's still there
11 N: [Mm hm,] : [Mm hm,]
12 C: a[nd the]re's two mor[e:,] .hh presuming [(0.2)] that
13 N: [Mm hm,] [Mm hm,] [Mm hm,]
14 C: prognosis will now be shorter.
15 N: **1-->** .tckhhh eh eh: not not (.) not necessarily. >You know i- i
16 it< again it depends: of- .hh >so w::h- wher:e where

- 17 the new one's po:st um: [(.) p]o:st radiotherapy?
 18 C: [U::m]
 19 N: Mrs ((n[ame])) were they th-]
 20 C: [(?) that they were:] further ba:ck. B[ut I can't]
 21 N: [Further back]
 22 C: remember: w[hether] sh- .hhh coz the fir:st one she had
 23 N: [Ri:ght]
 24 C: re[mo:ved] wasn' terribly dee:p. >And I c[an't<]remember
 25 N: [°↓Yea::°] [Right.]
 26 C: whether she said these were: (.) l[ike] deeply embedded
 27 N: [Yeah,]
 28 C: or whether they[re quite] near the sku:ll as well.
 29 N: [↓Ri:ght,]
 30 N: Ye::s, [yea:h yea:h.
 31 C: [.hhh but certainly further ba:ck.
 32 N: Ri:[ght,
 33 C: [Toward the ba:ck of the head.
 34 N: **2-->** Ri:ght. Ri:ght. Yea:h .hh yea- so i- i- it (.) doesn't
 35 al:ways >you know< you ca:n't always just say: that-
 36 precisely tha::t 'coz agai::n you know people ca:n be
 37 quite >you know< b- can >you know< can be qui:te you-
 38 quite va:riable wi' them.
 39 C: M[m::,
 40 N: [.hhh You know tha- you know themselves.=So i- it's it's
 41 mayb- it's maybe no:t (0.2) def- you probably think #i-#
 42 though this- thi:s is this is possible. >I ↑think that's
 43 probably the ea- the- the- (p-) .hh I'm not try:ing to be
 44 eva:sive here or not answerin[g]your questions ((name)).
 45 C: [No.]
 46 N: .hhh probably would be: that i:s a possibility ye:s because
 47 of- there has been further .hhh >y'know y'know< fur- you
 48 know further development ther:e within (.) >y'know y'know<
 49 with:in y- the area. You know within your mum's brai:n so,
 50 .hhh so tha:t is a possibility. You know it is: a
 51 poss:ibility that tha[:t m]ay be the .hhh that y'know that
 52 C: [Yeah]
 53 N: **3-->** that may be the ca::se u:h .hh and agai:n you would get
 54 guidance of how: you know you how we::ll your mum is: .hh
 55 and how we:ll she's she's ma:naging to do her: dai:ly
 56 >you know< (.) daily activities or per:sonal activities
 57 and things. .HHH E[ven t]hings that that's- some things

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58 C: [Yea:h]
59 N: and .hh you get a bit more gui:dance from tha:t starting
60 to cha::nge where .hh she's no:t as a:ble (.) you know to
61 do: th[ese]things. .hh She's becoming more ti:red .hh you
62 C: [Sure]
63 N: you know she's maybe wanting to ta:ke to her be:d more:
64 she's maybe wanting to re:st. You k:[:now] to rest a bit
65 C: [Yeah]
66 N: more: s[o .H]HH >you know< th- these are some of the si:gns
67 C: [Yeah]
68 N: that might be (0.3) .tck that may be hel:pful to loo:k you
69 know t- y- y::ou know to look- you know to look a::t...

Transcription Notes

- Line 2 - The nurse is about to say something here but the caller's overlap is louder and so the sound is indistinguishable. I can hear her production of some first syllable but I am unsure what it is.
- Line 43 - "the ea-" sounds like the start of "easiest".

Step 1: Addressing the prognosis talk (with an answer to a prognosis question)

- The nurse first answered the caller's question with what is essentially positive news: "tckhhh eh eh: not not (.) not necessarily. >You know i- I it< again it depends: of- .hh >so w::h- wher:e where the new one's po:st um: [(.) p]o:st radiotherapy?"(lines 25-7). She displayed some difficulty here, noticeable in her lipsmack, the fumbling on "not" and the way she abandoned information-giving to solicit more details from the caller. They discussed the location of the patient's tumours with the caller confirming her thoughts that they were toward the back of her head (lines 20-33).

Step 2: Managing the caller's expectations - The nurse acknowledged this information with "Ri:ght" (line 34) and attempted to provide the caller with an answer (as she did in her turn at the start of this sequence). She pointed to the challenges in providing prognoses, "Yea:h .hh yea- so i- i- it (.) doesn't al:ways >you know< you ca:n't always just say: that- precisely tha:t 'coz agai::n you know people ca:n be quite >you know< b- can >you know< can be quite you- quite va:riable wi' them." (lines 34-38), but this was not an explicit explanation compared to the methods used to achieve this by the call-handlers in the previous extracts and she did not use this as a way to explain her inability to provide this information but further attempted to answer the caller's question. This resulted in a significant amount self-repair before she was placed in a

position where she explicitly accounted for her interactional behaviour “.hh I’m not try:ing to be eva:sive here or not answerin[g] your questions ((name))” (lines 42-44) . This was similar to the nurse in the previous extract (5.6) who also had to eventually admit she did not have all the relevant information with “I don’t know” (extract 5.7, line 70). The sequence continued with much repetition, with the nurse reiterating her answer described by the caller as a “possibility” (lines 56, 60 and 61) - a more neutral answer compared to her first turn (line 15) but an answer nonetheless.

The nurse closed this sequence by returning to a topic the pair discussed in the main body of the call about symptoms the patient might experience in the future (line 53). She did not check the caller’s understanding throughout this sequence, nor did she recommend questions the caller could ask in a future appointment with medical professionals who are, logically, most likely to have the answers she was looking for.

The importance of managing caller expectations and constructing these requests as ones for doctors to handle is perhaps most evident in this final extract. The caller, a daughter of a male patient with stage four lung cancer, is pursuing a response about the patient’s life expectancy (the earlier part of this call was analysed on pp. 109-110).

Extract 5.9

MCREL46/Nurse8, Nurse response to caller request for a prognosis (orientation to a difficult future topic), [11:30-14:14].

- 1 C: ...I:: no: I I: appreciate tha:t and that was[:: >y]ou know
 2 N: [↓Mm::]
 3 C: that was< quite .hh I I understa:nd tha:t but, (.) [i:]
 4 N: [Mm::]
 5 C: if he’s going to have to go through all the pai::n and
 6 everything else: j[ust] to prolong his life for wha:t for
 7 N: [Mm:]
 8 C: another .hh you know few months, he might not d- >he might
 9 decide< n- he doesn’t want tha:t and I:- that’s why I need
 10 t[o kn]o:::w (.) well we:: [(.) then I can explain to hi::m
 11 N: [.tck] [Well]
 12 C: you kn[ow if] i:t’s gonna be: .hh #[i:::g]# (0.3) and (.)
 13 N: [Mm:::] [Mm,]

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14 C: and he's not really prepared: >sort of talk< can't really
15 tell us tha::t and I::, (.) >and I know< they can't play
16 Go:::d but I think [(.)] they should be a[ble]to tell
17 N: [Mm::,] [.HHH]
18 C: me?
19 (0.5)
20 N: **1-->** .HHH We:::ll >y- y-< you kno:w it's very it's very
21 difficult to give a prognosis for fo::r fo::r for someone
22 becau:::se .hhh it depends on the:: it depends- if if they
23 have treatment .hh it depe::nds on the benefit that people
24 get from treatment. (0.2) .hh U:m sometimes doctors can
25 u:::se u:::m .hh (0.3) can use a specific too:::l that that
26 they ha::ve an online tool they can look at .hh maybe .hh
27 y- you know people the same age as your da::[d] the same
28 C: [Mm]
29 N: the same diagno[sis] the sa:me treatment that maybe he
30 C: [Mm]
31 N: would possibly ha::ve. [.hh] u:::m, (0.3) .tck and the:n
32 C: [Mm:]
33 N: (0.2) you know g- give a kinnae >a a< kinnae:: prognosis
34 but again it would be an average prognosis=
35 C: =Yeah but how do I fi[nd that] informatio:n? (.) Who who:
36 N: [because]
37 C: would give me that information[n.
38 N: [Th- the specialist.
39 C: O:::h (.) the oncologist.
40 N: Ye:::es
41 (0.2)
42 N: Ye[a::h. It wo]uld be: it would be the uh it would =
43 C: [.tck ri:ght]
44 N: = b[e: the spe- .hhhhhhh]
45 C: [I thought you might]be able to tell me tha::t.
46 (0.4)
47 N: **2-->** Well I:- I- I ca:- what I::: can give you:: is (.) do you
48 have access to th- interne:t?
49 C: Yea:h
50 N: .tck Oka:::y there's information o:::n the cancer
51 resea:rch website. Now i[t's v]ery average information,
52 C: [↓Yea.]
53 N: it's no:::t hh .hhhh you know it talks about the different
54 stages of: of of (.) li:ke bowel cancer and it ta:::lks

55 u::m >about the< possible (.) prognosis.

56 C: Y[es,

57 N: [Now (.) .hh this is not aimed at your da::d, (.) u:::m,

58 .hh this is very very general.

59 (0.2)

60 C: O[kay,]

61 N: [Very] general. .hhh And there's nobody can sa::::y,

62 .hhhhh (.) there's nobody can sa:::y (.) exactly what's

63 going to happen to::: a speci[fi]c individual.

64 C: [w-]

65 C: Mm[:::]

66 N: [bec]ause everybody's so: different u:::m,

67 C: Well that's the bi[t th]at's frustra:ting isn't it because

68 N: [.tck]

69 C: y[ou your] can't just .hhhh

70 N: [That's-]

71 N: **3-->** .tck Yes yea::h. (.) U:::m, (.) ↓I kno:w. An- and it's

72 becau::se it's because we're all so different. >I

73 mea[n< s]ome people .hhhh some people who have treatme::nt

74 C: [Mm::]

75 N: get more: can get more benefit fro::m the treatment [fr-]

76 C: [Mm]

77 N: U::m (.) you kno::w other other: people (.) don't get a-

78 don't don't ge[t much] benefit, (.) so it really, (0.5)

79 C: [mm:::]

80 N: you know we're all .hhhh (.) we're all we're all so::

81 differen[:t. U)::m .hh but is it somethin' is there

82 C: [Mm::,]

83 N: somethin' hhh I mean cuz you're you're you're sayin-, (0.5)

84 .tck that your dad >but I mean< if your dad's: going to

85 have any any treatment he would need to give his permission

86 f[or it to happen]

87 C: [No exactly but I] ca::n't...

Transcription Notes

- Line 12 - The transcription of “[i::g]” is the closest thing to how this word/noise sounds. It could have been the start of “exactly” (one could pronounce the first bit as “ig”) but the nurse’s overlap makes it hard to hear.
- Line 33 - “Kinnae” is a Scottish pronunciation of “kind of”.
- Line 71 - The nurses delivery of “↓I kno:w” sounds empathic.

Step 1: Managing the caller’s expectations - The nurse first described the difficulty health care professionals have when providing a prognosis based on

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the uncertain matter of how patients will respond to treatment (lines 20-24). She further explained that doctors sometimes use an online tool when determining prognoses and says that this might be used to estimate her father's; although she qualifies this with "but again it would be an average prognosis=" (line 34). Despite the nurse explaining the difficulty, however, the caller further asked where she could find this information. This turn is perhaps based on the caller's understanding of an "online tool", one she may have considered available on the internet (and so to her); but also may have been related to the nurse's turn which highlighted the difficulties in providing prognoses but which did not explicitly say *she* could not provide one. This theory is consistent with the caller's turn at line 45 which conveyed her expectations about what the nurse could tell her: "I thought you might]be able to tell me tha::t." (line 45).

Step 2: Addressing the prognosis talk (with general information) - Rather than the nurse describing the remit of her expertise here and advising the caller to make an appointment to speak with the patient's consultant (they have just established the caller needs to), the nurse directed the caller to *Cancer Research UK's* website (lines 47-51). She qualified her provision of this website by repeatedly emphasising the challenges associated with determining prognoses: that the website will only provide the caller with "very average information" (line 51), that it can only talk about a "possible (.) prognosis" (line 55), that information is "very very general" (line 58) and finally, "hhh And there's nobody can sa:::y, .hhhhh (.) there's nobody can sa:::y (.) exactly what's going to happen to::: a specif[ic individual. [bec]ause everybody's so: different u:::m" (lines 61-66).

Step 3: Addressing the prognosis talk (with general information) - It is perhaps the way she laboured this point, particularly her use of extreme came formulations, *very average, nobody can say* (Pomerantz, 1986), that the caller further complained about her situation: "Well that's the bi[t th]at's frustra:ting isn't it because y[ou your] can't just .hhhh" (lines 67-69). The nurse repeated earlier information about everybody being different, the varying ways patients respond to treatment (lines 71-81) and the sequence continued with the caller describing her dilemma to the nurse.

In summary, nurse responses to prognosis requests displayed their orientation to a 'difficult future topic' (Parry, Land & Seymour, 2014) which was evident in the content of these discussions (repetition, conflicting information and advice, misalignments between the participants) as well as how this information was delivered (speech perturbation, pauses, lip smacks and repetition). Although the nurses often used techniques to highlight the remit of their expertise, they overwhelmingly followed these turns by engaging with the prognosis talk, either by providing a prognosis or answering a prognosis-related question. So on the one hand they attempted to minimise caller expectations about what information they could provide, while on the other hand they raised caller expectations by providing specific information about the patient's cancer type.

The call-handler in the first extract (5.6) constructed the caller's request as 'doctorable' early on in the sequence and provided the caller with relevant questions to ask when she returned to the hospital, using the following 'steps':

1. **Step 1:** Advice to speak with the patient's doctor;
2. **Step 2:** Addressing the prognosis talk (with information about prognosis-related matters; and
3. **Step 3:** Sequence closure (checks understanding).

The nurse thus addressed the caller's request without providing an actual prognosis (something the call-handlers are not in a position to provide).

5.4 Conclusion

The objective of this chapter was to investigate how requests for a prognosis were managed on the cancer helpline, a topic not researched before despite the widely-cited difficulties about discussing such matters. There are three significant findings from this chapter: 1) Callers typically requested a prognosis using a direct vocabulary, one that used language associated with timelines such as "prognosis", "life expectancy", "length of life", and so on. The callers aligned with the services on offer from the helpline and asked for general information rather than individual patients. 2) Nurses used techniques to manage caller expectations about the remit of their expertise but then often followed these turns by talking about prognoses in ways that resulted in problems during these sequences. 3) Nurses sometimes advised callers to

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speak with the medical professionals involved in the patient's care however I showed that this advice needed to be placed early on in the sequence so it constructed the request as 'doctorable'. All in all, these findings showed that call-handlers oriented to these discussions as 'difficult future topics' (Parry, Land & Seymour, 2014). Reasons for these findings could be attributed to the challenges of helpline work, such as the difficulty of providing callers with the information they require while not going beyond the remit of their expertise. The nurses were trying to help callers with the assistance they needed but, similar to doctor-patient interactions, talking about what will happen to a patient in the future is particularly difficult to discuss, especially in relation to a complex disease such as cancer. And, again similar to physicians, the nurses are not provided with formal guidance about information that is suitable to provide in response to such requests.

In the final empirical chapter, I will discuss how the participants transitioned from such information-giving sequences into the closing phase of the call. This could also pose problems for the participants, especially if the nurses were unable to provide callers with the assistance they required (as with some of the cases here).

Chapter 6: Bringing the Calls to a Close and Expressions of Caller Satisfaction

6.1 Introduction

When callers telephoned the helpline, they were seeking information, advice, guidance and reassurance on a considerable range of medically-related matters including concerns about symptoms, about their particular cancer type, about treatment, about uncertain future matters, as well as many more. The 'business' of the encounter was often multifaceted with callers bringing two or more problems for discussion. The nature of the callers' problems may have been relatively straightforward and required the provision of information the nurses were able to provide; or they may have been outside the remit of the call-handlers' expertise. Both prognosis requests (Chapter 5) and concerns about troubling symptoms (Chapter 4) could cause problems for the participants because the nurses could not provide callers with the assistance they required. In these cases, the matter of whether the caller had been 'helped' became a real-time issue for the participants during the calls. Whilst the nurses did everything they could to assist callers with their problems, sometimes they could not meet their expectations.

Research on both ordinary social calls and calls for institutional assistance has found that the person who places the call overwhelmingly informs the other speaker when the 'business' of the encounter has been completed, usually by producing a move to bring the call to a close (Schegloff & Sacks, 1973; Button, 1987; Zimmerman, 1992; Raymond & Zimmerman, 2007). In institutional calls, this is usually accomplished with the pro-forma appreciation 'thank you' which indexes the benefactor (call-handler)/ beneficiary (caller) status of the participants for the services rendered during the interaction (Zimmerman, 1992; Raymond & Zimmerman, 2007; Clayman & Heritage, 2014). There is accumulating evidence to suggest that closing moves can also be used strategically to express varying levels of satisfaction with the outcome of the call (Clark & French, 1981; Zimmerman & Wakin, 1995; Raymond & Zimmerman, 2007). This evidence, however, is based on monotopical calls (i.e. when the caller has one main enquiry) rather than calls of a more complex nature, such as calls placed to helpline organisations.

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In this chapter I explore how these cancer helpline calls were brought to a close and how within these moves callers expressed differing levels of satisfaction with the services received. In the following paragraphs I will first discuss what is referred to as the “closing problem” (Schegloff & Sacks, 1973) and how it is managed collaboratively in mundane social interactions (Button, 1987; Patterson & Potter, 2009; Ekberg & LeCouter, 2014) and institutional settings (Clark & French, 1981; Heath, 1985; Zimmerman, 1992; Zimmerman & Wakin, 1995; Robinson, 2001; West, 2006; Raymond & Zimmerman, 2007). A case will be made that closing conversations is a tricky interactional activity to accomplish *generally* but with the additional contingencies associated with institutional interactions, and this helpline in particular, closings were more difficult to manage. The analysis will outline the architecture of closings and how closing sections were routinely opened, before showing that it is within these closing moves that callers expressed their varying satisfaction with the service(s) received. The findings from this research will contribute to an understanding of how helpline calls are brought to a close (there is an evidence gap in current literature) as well as endogenous measures of satisfaction.

6.2 Part one: Bringing Conversations to a Close

6.2.1 The Collaborative Nature of Closings and the “Closing Problem”

An influential paper about conversation closings by Schegloff and Sacks (1973) identified what they labelled the “closing problem” and discussed how it was managed by participants during ordinary social telephone calls. This problem is primarily associated with two inter-related matters. First, the turn-taking organisation of interaction ensures that there are mechanisms in place for talk to continue (turn transition, conditional relevance, speaker selection, and so on) but it does not specify when, or how, conversations should end. The first problem faced by participants, then, is how to suspend this turn transition relevance rule in a way that is recognisable as terminating talk rather than continuing on topic. Related to this problem is also the matter of “unmentioned mentionables”. Each participant may bring a range of “mentionables” for discussion during the interaction. The first “mentionable” has a “slot” in the opening section of the call, known as the “anchor position”

(Schegloff, 1986), but the rest are locally produced on a turn-by-turn basis¹⁸. Taking these two elements together, the “closing problem” is thus how participants close the conversation in ways that are recognisable as “doing closing” and which allows for hitherto “unmentioned mentionables” to be raised for discussion before the call terminates. Schegloff and Sacks (1973) found that this is managed collaboratively through the initiation of a closing section.

Extract 6.1

Social telephone call closing (taken from Schegloff & Sacks, 1973).

- | | | | | |
|---|----|---------|---|----------------------|
| 1 | A: | Okay | ← | Pre-closing sequence |
| 2 | B: | Okay | | |
| 3 | A: | Goodbye | ← | Closing sequence |
| 4 | B: | Goodbye | | |
- End of Call.

The closing is opened at line one with the first pre-closing component “Okay”. The first move is only a *possible* pre-closing move – it only becomes an actual pre-closing move if the second speaker aligns and produces a second “okay” (Schegloff & Sacks, 1973). The component “okay” functions multifariously but it regularly occurs at transitional moments, when speakers are moving on to new topics or next activities, such as closing sections (Beach, 1993; 1995). The component functions as a pre-closing move because it is bereft of topic continuation and acts as a “free-turn” of talk; a way for the first speaker to show they are “passing” on an opportunity to extend the conversation (Schegloff & Sacks, 1973). The pre-closing turn may contain the stand alone “okay”, or the “okay” may be deployed in turn-initial position: “...as *responsive* to [a] prior turn and *preparatory* in movements to what is offered as relevant for ensuing talk” (Beach 1993, p. 339 emphasis original). Once *both* speakers have displayed a readiness to close, a “warrant” for termination is created and an exchange of terminal utterances are produced. The final utterances,

¹⁸ There seems to be a preference for some topics to be “shaded” into the surrounding talk rather than being placed in first position as the reason for the call. For a discussion of this, see Schegloff and Sacks (this paper) and Sacks’ (1992a) on “tellability”.

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“goodbye/goodbye”, complete the closing section and the final click of the telephone terminates speaker contact.

There is no guarantee upon the production of the first-closing move that speakers will reach termination. It is for this reason that closings, similar to conversation openings, are considered to be an interactional *accomplishment* due to the multiple ways they could unfold depending on the behaviour of each speaker (Schegloff & Sacks, 1973; Schegloff, 1986). Button (1987, 1991) provided a comprehensive account of the prevalent sequences that form, in his words, “minimal” and “drastic” moves out of closings. A minimal move preserves the sequential implicativeness of closing and participants return to the business of terminating the conversation after the brief move is made. Drastic moves, in contrast, re-open talk and closing may not reoccur until much later in the call. Button (1987) identified seven sequences that regularly occur within closing sections. One minimal move is arrangement-making which has recurrently been identified as a regular activity done within, or near to, closing sections (Schegloff & Sacks, 1973; Button, 1987, 1991; Ekberg & LeCouter, 2014). Arrangements are regularly done here because:

“...[they] provide an orderly relationship between ‘this’ encounter and a ‘future’ encounter – as opposed to ‘next’ encounters being by chance...by providing for a ‘future’ encounter, they may propose that a current encounter could be appropriately concluded and may, thus, propose that further topics may be ‘reserved’ for ‘the next time’, or are, at least, unnecessary now” (Button 1987, p. 105).

The arrangement may be the last topic of the conversation and “overspill” into the closing section, or the arrangement may be used to initiate the first closing move. Here is an example of the former:

Extract 6.2

Arrangement-making in social telephone calls (taken from Button 1987, p. 108).

- 1 Pete: I'll see you Tuesday.
- 2 Marv: Right.
- 3 Pete: OK Marv[in.
- 4 Marv: [You-you're alright? You can get there?

5 Pete: Yeah.
 6 Marv: Ok.
 7 Pete: Ok. Thank you.
 8 Marv: You bet bye
 ---- End of call.

The arrangement was confirmed at lines 1 and 2 with Pete's move to the future, "I will see you", and Marvin's acceptance, "right". Pete then produced a turn bereft of topic continuation, "OK Marvin", which formed the first possible pre-closing move (line 3). In overlap, Marvin asked if Pete is able to get to the destination (line 4) and it is here where the arrangement "overspilled" (Button, 1987) into the closing section. The overflow checked Pete had transportation to the location and it is likely that the issue of Pete's transport had not come up in the main body of the call¹⁹. The checking is thus an "afterthought" (Schegloff & Sacks, 1973) and is placed in the closing section to ensure Pete had transportation before the call ended (necessary if Pete was going to attend this arrangement). It is the overlap on Pete's turn at line 3 which showed Marvin's orientation to this activity as unsuitable for the closing environment - the urgency of overlapping here to ensure the call did not terminate before Pete's access to transportation had been checked. This matter should have been confirmed before the arrangement was finalised at line 1. Participants use other "misplacement markers", such as "*by the way...*" or "*I should have said earlier but...*", to show they are moving away from closing with another interactional activity (Schegloff & Sacks, 1973).

Finally, Patterson and Potter (2009) examined the pre-closing sequences of social telephone calls between a disabled adult in a care home and three of her family members. Their analysis, utilising the principles of discursive psychology, focussed on who initiated the first possible pre-closing move and their different designs. They identified three practices for opening a closing which they claimed displayed a "caring", affiliative stance toward the other

¹⁹ I say "likely" because Button (ibid) does not provide contextual details about the call other than that the arrangement was made in the closing section.

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speaker. One of the pre-closing sequences involved an interrogative plus account design²⁰, shown here in the following example.

Extract 6.3

'Other attentive' social call closing (taken from Patterson & Potter 2009, p. 14).

1 Sue: Everybody's havin' their supper.°tha-s.°
2 (0.4)
3 Sue: ((called to another person)) CARRIE can
4 I I have my supper in a bi:t. (.)
5 when I've finished ma pho:ne.
6 (1.9)
7 Mum: Well do you ↑want. to ↑go sweetie.
8 and get [yer s]upper=
9 Sue: [not-]
10 Mum: =and watch. the rest, of Indiana?

It is evident from Sue's turns at lines 1 to 5 that she had another activity (her supper) to engage in other than the telephone call with her mother. Mum, in hearing this, and also her knowledge of what Sue was doing prior to the telephone call (see line 10), used this information to initiate the possible pre-closing move with the interrogative "Well do you want to go sweetie" and the account "and get yer supper and watch the rest of Indiana?" (lines 7, 8 and 10 respectively). Mum is said to demonstrate "caring" because she was closing the call in the interests of her daughter by allowing her to join in with supper and watch the end of the film Indiana Jones rather than Mum ending the call for her own interests (for example, if she had something else she wanted to do). Although not referenced in the authors' analysis the turn design is, in the words of Jefferson (1984), "other-attentive", as it displayed sensitivity to the needs of the co-participant.

The previous extract also raises additional points about how closings are opened which are not raised by Patterson and Potter (2009). An early lecture of Sacks (1992a)²¹ was concerned with whether external factors to telephone calls

²⁰ Other accounts included an [announcement] plus account format and a [directive] plus account format.

²¹ Spring 1971, "Caller/Called".

such as the identity of “caller/called” could be brought to bear in understanding the structural organisation of the interaction. He claimed that the identity of telephone interactants is noticeable in the opening moments of calls, represented in the A-B-A-B structure: Caller (summons), Called (hello), Caller (greeting), Called (greeting); and then again in the closing as it is frequently callers (rather than called) who produce the first closing move. A device callers’ regularly use for opening closing sections is a “closing offer”. This involves “caller” asking what “called” is doing early on in the conversation, “*what are you doing*”, “*just about to eat dinner*”; “saving” the answer; and then using this information to initiate the first move into the closing section, “*okay I will let you get back to your dinner*” (ibid). It is likely that Mum in the extract from Patterson and Potter (2009) had asked a similar question at the beginning of her conversation with Sue for her to know that Sue was watching a film (see Mum’s turn at line 10)²².

6.2.2 Closing Institutional Encounters

There are additional contingencies associated with interactions in institutional settings which make closings more difficult to manage than participants in social talk. These contingencies are related to: 1) participants use a restricted range of practices in designing their talk in institutional settings (Drew & Heritage, 1992) so the repertoire of closing moves described in social interactions are not available in this context; 2) these interactions are often governed by time with the institutional representative working towards a schedule; and 3) the ‘business’ focus of these encounters usually dictates when they should close (that is, when that business has been completed).

Primary care consultations, at least in the UK, are organised around six key interactional activities and last for approximately ten minutes. This standardised organisation is efficient in terms of diagnosing and treating medical problems, as well as enabling physicians to examine multiple patients per day (Byrne & Long, 1976). Patients are provided with one “slot” to present their concerns at the start of the encounter as doctors then govern the

²² Without knowing the contextual details preceding the extract from Patterson and Potter (2009) I can only surmise that a “closing offer” was made. Regardless of whether this is the case, though, the point is that closing offers are regularly used to initiate closing sections. This will be discussed in my own analysis of the Macmillan calls.

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transition into the next phases of the visit (e.g. history-taking to diagnosis, diagnosis to physical examination, and so on.), including the closing section. Research has found that this structural organisation and the practices doctors use to open closings are two factors that may impede patients from raising the full spectrum of their concerns. This can result in patients raising “mentionables” in closing environments, known as “door-knob” concerns (White, Levinson & Roter, 1994; White *et al.*, 1997; Robinson, 2001; Heritage *et al.*, 2006) or leaving the consultation with unmet needs, which could have negative implications upon patient satisfaction and treatment adherence (Robinson, 2001; Heritage *et al.*, 2006). Robinson (2001) identified two physician practices for opening a closing section including: 1) arrangement making (e.g. for a future appointment or prescription) and 2) the solicitation of other concerns (e.g. *anything else I can help you with*). Robinson (*ibid*) argued that both of these practices prevented patients from raising additional concerns (if they have any) because: 1) in the first sequence, the doctors had orientated to the future and in doing so, as with arrangements made during social talk, is proposing that other business may be reserved for some future time (Button, 1987; 1991); and 2) in the second sequence, although the doctor used a topic-elicitor, research has found that the design “anything else” actually impedes patients’ from raising additional concerns because the turn is negatively polarised to prefer a “no response” (Heritage *et al.*, 2006; Heritage & Robinson, 2011). Furthermore, doctors are generally looking away from patients during both of these sequences which also contributes to the lack of uptake from patients who have multiple concerns (Robinson, 2001). Recommendations from this work suggest doctors should solicit further concerns after the patients’ initial presentation in the opening phase of the encounter, they should hold the patient’s gaze when doing so, and the solicitation should be designed with “something else” which prefers a “yes” response (Robinson, 2001; Heritage *et al.*, 2006; Heritage & Robinson, 2011)²³.

The closings of calls for institutional assistance over the telephone, similar to ordinary social calls, are overwhelmingly brought to a close by callers. This is frequently accomplished with a pro-forma appreciation, *thank you [for your*

²³See Heath (1985) and West (2006) for other analyses about how medical visits are brought to a close.

help] (Clark & French, 1981; Zimmerman, 1992; Raymond & Zimmerman, 2007; Heritage & Clayman, 2010). Research so far has focused on institutional encounters where the callers' 'business' is monofocal (i.e. focussed on one problem), such as calls to directory enquiries (Clark & French, 1981) or calls to the emergency services (Zimmerman, 1992; Zimmerman & Wakin, 1995; Raymond & Zimmerman, 2007). These moves index a benefactor (call-handler)/beneficiary (caller) relationship of the participants as the caller is essentially displaying 'gratitude' toward the services received during the call (Heritage & Clayman, 2014). The moves are often placed in sequential environments when an outcome or resolution has been reached (e.g. a confirmation an ambulance will or will not be sent to a named address) and are closing implicative because they display that the caller's 'business' has been attended to during the call (Zimmerman, 1992; Zimmerman & Wakin, 1995; Raymond & Zimmerman, 2007). It should be noted that while appreciations *display* a sense of gratitude, there is evidence to suggest that they can be used strategically to bring the call to a close rather than appreciating services provided by the other speaker *per se*. The following extract, for example, comes from the closing section of an emergency call as the call-handler had just agreed to send assistance to the caller's address. Note the caller's attempt to reopen their request at line 2 and the call-handlers use of an appreciation in response (line 3) to keep the call on a closing trajectory.

Extract 6.4

Emergency call closing section (Zimmerman and Wakin 1995, cited in Heritage & Clayman 2010, p. 84).

- 1 911: We'll get somebody there right away.=
 2 Clr: Maybe emergency rescue?
 3 911: Thank yo[u].
 4 Clr: [Thank you.=
 5 911: Mm bye.

In this case, the pro-social expression of gratitude is being used as a strategic resource to exit the call rather than appreciating the services provided by the caller (i.e. that they brought a problem to the attention of the institution) (Heritage & Clayman, 2010).

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In summary, participants are faced with a distinct “closing problem” when ending conversations which makes them a tricky interactional activity to accomplish. Closings are managed through the initiation of a closing section which creates a warrant for closing by ensuring both parties have raised all “mentionables” before the interaction ends or, at least, provides an opportunity for unmentioned mentionables to be raised at a future time. Closing sections are managed collaboratively in both social and institutional settings although the added contingencies associated with institutional talk often make the “closing problem” more difficult to manage. Research on closing institutional encounters has so far focussed on face-to-face medical visits and calls for emergency assistance.

To my knowledge, there is no current investigation about how helpline interactions are brought to a close. This is important based on the added contingencies associated with helpline interactions, and this helpline in particular, which could make closing moves more difficult to accomplish. For example, the business of these encounters may involve a discussion of problems that are of a complicated and sometimes delicate nature and callers may bring a range of these mentionables which may not have an obvious resolution (compared to a prescription or blood test in doctor-patient interactions). The matter of whether the caller has been ‘helped’ thus becomes a real-time problem during these calls. Similar to other institutional representatives, Macmillan call-handlers are not provided with formal guidelines on how to “do” call closings which may become problematic, especially if the caller’s problem is not one Macmillan can assist with (as we saw in the previous chapters), or if the caller is distressed. The difficulty associated with closing cancer calls is captured in a quote from an interview study with Macmillan call-handlers:

*“You do find that these calls tend to be **circular** and you do try to use some closing **techniques**. I think we've discussed that before – and you get lots of – yes but I can't – because of this, because of that – and closing those calls or **moving them forward** – are incredibly **difficult**”* (Leydon *et al.*, in preparation).

The aim of this chapter is to fill this evidence gap by investigating the practices participants used to bring the cancer helpline calls to a close. In the next section I will describe the main findings from this research focussing on how closings are opened, by whom, and the consequences this had upon the participants reaching termination.

6.2.3 Bringing the Macmillan Calls to a Close

The detailed analysis found that closing sections were overwhelmingly opened by callers with the appreciation, *thank you [very much/indeed/for your help]*. There seemed to be an orientation by both participants for callers to make the first closing move which is represented statistically in the amount of times this occurred across the corpus (67%), and in the tentative first moves made by call-handlers if a move from the caller was not forthcoming. These moves were usually placed in sequential environments after the participants have reached some form outcome or resolution for the caller's problem(s) during the main body of the call (e.g. the nurse had recommended the caller visit their GP, the caller had indicated they have understood the nurse's information, the nurse had told the caller they could not answer their question, and so on). Two cases were excluded from this analysis. They both followed the pattern of caller and call-handler initiated first closing moves but the call terminated before the 'business' of the encounter was dealt with: one caller ended the call prematurely because their neighbour returned their dog from a walk; and the second call ended because the caller did not have the documents about his treatment which the nurse needed in order to provide the requested information. The analysis was thus based on 97 closing sections.

I will first describe the architecture of call closings based on whether the closing was opened by the caller or call-handler.

6.2.3.1 Opening a Closing: Caller Initiated

Caller closing moves were overwhelmingly placed at junctures when the participants were disengaging from the previous information or advice-giving sequences. This was often accomplished with repeated turn constructions or displays of understanding and may have been negotiated over several turns between both of the participants. The caller in the first extract, for example, a friend of a female patient with breast cancer, asked the nurse a series of

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questions throughout the call about breast cancer and its treatment, and just before this extract she asked why her friend was offered surgery followed by chemotherapy rather than in the reverse order. The nurse informed the caller that breast cancer treatment is sometimes ordered this way because it preserves more of the breast after treatment (thus reducing the need for a full mastectomy). We join the participants as the caller was acknowledging this information.

Extract 6.5

MCREL30/Nurse6, Caller initiated closing [14:34-14:53].

- 1 C: That's that yeah: actually that's probably yeah that is
2 i[s what the]y said originally. They've said if we can=
3 N: [°Yea:::h,°]
4 C: =shrink =it do:wn then we'll probably go for the
5 ↑lumpectomy.
6 N: Ye[a:::h
7 C: [As opposed to the mastectomy so th[at that's why=
8 N: [which of cou::rse
9 for-
10 C: = they took that li:ne.
11 N: Yea::h for lots of women it's much more preferable. .hhh
12 (0.2)
13 C: Yeah. (0.4) Yea:h I think that's probably why they took
14 that line actual[ly].
15 N: [Mm]:: hm[::
16 C: [Ok]ay:. [Thank you very much:.
17 N: .hh You're welcome. If there's anyt[hin' el]se at a:ll
18 C: [>°Okay°]
19 N: do do give us a call ba::ck. [°Are y-° ↑Are you]
20 C: [I will do thanks.]
21 N: happy for me to= just to keep a >sort of< brief ↑no::te
22 of what we've talked a[bou:t]
23 C: [↑Ye::s] of cou:rse:: (.) yeah.
24 (.)
25 N: That just h[elps]if you do phone ba:ck and it's all (.)=
26 C: [Yeah.]
27 N: =°k[ept°]confide:ntial bu- but take care and if there's=
28 C: [Okay.]
29 N: =anything else at all: just give us a call back.

30 C: Excellent (.) Thanks very much:.
 31 N: Tha::nks ↑bye:.
 ---- ((End of call))

The caller's turns at lines 1-15 worked to disengage from the previous information-giving sequence. This was accomplished with her agreement with the nurse's information (see the repeated use of "yeah") and her repeated turn constructions: "That's that yeah: actually that's probably yeah" (line 1), "so th[at that's why they took that li:ne" (lines 7 and 10) and "Yeah. (0.4) Yea:h I think that's probably why they took that line actual[ly]" (line 13-14). Schegloff (2011) argued that these repeats close sequences because they are bereft of topical continuation and so provide an opportunity for the participants to discuss other matters, or to close down the conversation completely. The caller further confirmed the previous sequence was closed and opened the closing section with her turn at line 16: "[Ok]ay:. Thank you very much:.". The 'okay' of this turn was backward looking and acknowledged, and thus closed, the information-giving sequence; and the second component, the appreciation, moved the participants forward towards closure (Beach, 1993, 1995; Schegloff & Sacks, 1973). This design made it explicit for the nurse that the caller's 'business' had been attended to, an important matter for this particular caller because she asked the nurse multiple questions (and so she showed that she was not going to ask anything else). The nurse reciprocated, and so aligned, with this first move with two closing implicative turns: an encouragement for the caller to telephone the service again should she require further information (lines 17-19) and a request to record details made during the call (lines 19-27). These moves were "minimal" moves out closings because they preserved the sequential implicativeness of closing at this particular "now" (Button, 1987). This was evident in the caller's next turn as she produced another (this time upgraded) appreciation, "Excellent (.) Thanks very much:.", and the call ended.

The closings in the next two extracts were similarly opened after the participants disengaged from the previous information or advice-giving sequence. The caller in extract 6.6 is a female patient who was diagnosed with Chronic Lymphatic Leukaemia (CLL). This extract starts as the nurse was responding to the caller's question about what would cause her death.

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Extract 6.6

MCPAT53/Nurse15, Caller initiated closing [5:00-5:16].

1 N: Sometimes it can be the cancer and other times it's other
2 things that would cau- can cause the dea::th. (.) Towards
3 the e::nd.
4 C: Mm::.. [But would it be] the leukaemia or th[e: lymph node]=
5 N: [(?)] [I- I- It's]
6 C: =cytosis
7 N: .hh We::ll (.) you know: i- it's difficult to say:,
8 some[times it] might be the leukaemia that would cau::se=
9 C: [Yea:::h]
10 N: =.hh[h other] times it might be that you get a really bad=
11 C: [Mm ↑mm.]
12 N: =chest infection that you just can't get rid of,
13 C: Su::re.
14 N: Erm:: and that you know that might be the (.) the cau:se.
15 C: I see::.
16 (.)
17 C: .hhh Oka:y. Thank you very ↑much.
18 N: Okay no problem you take care now
19 C: And you
20 N: If you've got any other questions don't hesitate to give
21 us a call back
22 C: Okay thank [you very] much indeed
23 N: [O:ka::y]
24 N: No problem you ta[ke care] now
25 C: [Bye bye]
26 N: Bye bye
27 C: Bye
----End of Call.

The nurse displayed difficulty answering the caller' question, first with her vague response at lines 1-2, "Sometimes it can be the cancer and other times it's other things that would cau- can cause the dea::th..."; and her explicit orientation to difficulty at line 7, "We::ll (.) you know: i- it's difficult to say:". She repeated the former construction throughout in reference to what "might" be the cause of the caller's death (see lines 1-2, 8 and 14). The caller oriented to the call-handlers difficulty with her acknowledgement tokens "Su::re" (line 13) and "I see::." (line 15) which displayed her understanding that the nurse

was unable to provide her with this information (i.e. she did not ask follow-up questions at this point like she did at line 4). The caller further closed the previous sequence with her “okay” and appreciation, “Thank you very ↑much.” (line 17) and the nurse aligned to this move with her own closing implicative turns (similar to extract 6.5). Note that the caller upgraded her appreciation at line 23, “Okay thank [you very] much indeed”, and this acted as the definitive move that progressed the participants to termination.

The caller in the final extract, a female patient, asked the nurse about whether she should take the two courses of antibiotics prescribed by her GP to remove a boil on her bottom before she starts chemotherapy. The nurse advised the caller to do so based on the matter that she may not be able to start treatment if it was still there. We join the participants as the nurse was expanding on her recommendation about why caller should take the antibiotics.

Extract 6.7

MCPAT52/Nurse9, Caller initiated closing [2:04-2:43].

1 N: So y[ou ar]e be::st off taking them just >no:w< an' make
 2 C: [Yeah.]
 3 N: sure: when you go on Mon:day to get your chemo that you
 4 te::ll them.
 5 (.)
 6 C: I will
 7 (0.2).
 8 N: E::rm,
 9 (.)
 10 C: [Oka:y.]
 11 N: [They might wa]nt- they might want to see it as we::ll just
 12 in c:ase it i:s infectious.
 13 (.)
 14 C: ↑Oh a:lright the[n].
 15 N: [Ye:s >if it-< if it's sti::ll infectious
 16 by Monday w- probably w:on't be by the:n >because it's<
 17 no:w onl[y Tuesday so you've got a week.
 18 C: [Ye:s]
 19 C: Yeah.
 20 N: Er::m you're best you know to: (.) >you know< (0.4) to get
 21 i::t, (0.2) .hhh to get rid of [(a virus)]

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22 C: [Ri:ght]
23 (0.2)
24 N: Other[wise it (??)
25 C: [↑Oh that's stra:nge though just starting
26 the[m af:- (.)] ha:te the co-amoxiclav .hhh
27 N: [I ↑kno:::w]
28 N: It's it's may:be to do with your antibiotics as we:ll.
29 C: It could be. Oh ri:ght.
30 N: Yea::h
31 C: O::h okay. .hh Well thank you th[ank you (.)>very] much<
32 N: [Oka::y no problem]
33 C: huh hh
34 N: Oka[y yo]u take care now by[e bye]
35 C: [Okay] [And you] bubyee.
----End of call.

Transcription note:

- Line 29 - the caller hiccups during the production of the word 'could'.

The caller acknowledged the nurse's recommendations with active acknowledgement tokens to display her understanding and agreement: "I will" (line 6), "oh a:lright then" (line 14), "It could be. Oh ri:ght" (line 29); and again in her move to open the closing with "O:h okay. Well thank you..." (line 31) (c.f. Heritage 1984 on how "oh" displays a move to an informed state). The nurse aligned to the closing with "Oka::y no problem" (line 32) and the pair progressed swiftly to termination.

Caller-initiated closings were thus relatively short in length and termination occurred in close proximity to the opening of the closing section. Although nurses regularly made moves out of closing, they were minimal, and related to institutional-specific tasks the nurses are trained to say before the calls end (especially the disclaimer about recording details from the conversation). The move back into closing was often accomplished with a second, often upgraded appreciation produced by the caller which acted as the final, definitive closing move. These moves, and the subsequent terminal exchanges, displayed the understanding of both participants that a warrant for termination had been mutually agreed (Schegloff & Sacks, 1973). Appreciations may seem unremarkable on their own, perhaps understood as participants simply going through the closing motions, but I will now provide cases when callers do not

produce appreciations as their first closing move and the ramifications this could have upon the closing section.

6.2.3.2 Opening a Closing: Call-Handler Initiated

Arrangement-making was previously discussed as a recurrent activity speakers do near and, or, within closing sections in both mundane (Button, 1987, 1991; Schegloff & Sacks, 1973; Ekberg & LeCouter, 2014) and institutional encounters (Byrne & Long, 1976; Robinson, 2001). The same activity occurred on the cancer helpline. The structure of the advice and information-giving sequences frequently involved the call-handler providing verbal information or advice during the main body of the call and then, and this depended on the nature of the callers' enquiries, offering to send the caller something tangible in the form of a Macmillan booklet or factsheet near the end of the sequence. Nurses may also have offered to send the caller a booklet early on in the call and then retrieved the offer to initiate a closing section, similar to the "closing offers" described by Sacks (1992a). The most common practice nurses used to open closing sections was through these arrangements but they were much less definitive than closing moves made by callers. They seemed to "nudge" callers towards the relevance of closing while still allowing for further talk.

Extract 6.8

MCREL28/Nurse1, Call-handler initiated closing [7:21-9:26].

((Summary: The caller is the daughter of a male patient with lung cancer. The caller was concerned that her father would not be able to look after himself properly if he returned home on his own after treatment due to his range of medical problems. Just before this extract the nurse offered to send the caller a booklet called *Caring for Someone with Advanced Cancer* which the caller resisted based on the matter that the family have a lot of written materials. In response, the nurse offered to send the caller a different booklet about *Breathlessness* and described why it would be useful for the patient. This extract comes toward the end of this sequence when the call-handler was describing why the booklet would be useful for the patient's needs)).

1 N: And I could put those (series)of booklets in as well for
 2 [you to just have a look] then if you think=
 3 C: [()]
 4 N: =they would be helpful for hi:m .hh you could pass them
 5 on,

((10 lines omitted re the patient "assimilating" written

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material better because of his trouble hearing)).

- 6 N: Mm::, (.) I mean it is very practical so it's got [very]=
7 C: [Mm::]
8 N: =practical kind of (.) you [know] (?) of information in it
9 C: [Yeah]
10 C: Yea:h=
11 N: =It so (.) .hh so maybe [(?)]
12 C: [No] that would be very good.
13 N: Okay the:n. .hh And if there is anything else that we can
14 do then obviously do:n't hesitate to get back to u::s
15 C: [(?)]
16 N: [U:::m] (.) and are you happy if I make a little note that
17 I've spoken to you today,
18 C: Yeah that's not a problem.
19 N: Okay then. ↑Anything else at the mome:nt? [(?)]
20 C: [U:::m no I
21 don't think so [()] (?)
22 N: [°Okay°]
23 N: Well if you think of anything just get back to us
24 C: Yeah I will do. Thanks very much indee:d for your help
25 N: Oka::y thank you:
26 C: Bu bye
27 C: B'bye
----End of call.

Extract 6.9

MCREL21/Nurse4, Call-Handler Initiated Closing [15.24 - 16.30)].

((Summary: The caller is the daughter of a male patient with bile duct cancer. The family have been informed by the patient's medical team that the patient's health had recently deteriorated but they have been unspecific about the details of how they know this. The call-handler advised the caller to get in touch with the medical team and also offered to send the caller a booklet about *Dying* earlier on in the call (not the sequence immediately prior to the closing section). When the call-handler referred to "that" at line one, she was advising the caller to ask the medical team about what they mean by deterioration)).

- 1 N: Nye::ah I mean perhaps give them a call and see .hhh >see
2 what they mean< by that=I can certainly send you this
3 information like I say about
4 [y- y- you know °wh- what happens°]
5 C: [Yeah that would be very useful ac]tually.

6 N: We've taken your address have[n't] we, my=
7 C: [Yes]
8 N: =colleague took your name and [add]ress:: so::=
9 C: [Yes]
10 N: =.hh That's fine I can certainly pop that in the
11 post >and it is first class< so hopefully it will
12 be with you:: sort of you know .hh tomorrow.
13 C: Nyeah. °Probably°
14 N: Was- was there anything ↑else at all or,
15 C: No that's it, [that's] really helpful=
16 N: [Yeah?]
17 C: =T[hank you for that.]
18 N: = [Okay well we're he]re from nine till eight Monday to
19 Friday so if there is anything else you
20 you know I can make a note of: today's call >if that's
21 okay with you j[ust a very brief]=
22 C: [↑Yes, that's fine]
23 N: =summary< [and] it's all confidential .hhh erm but=
24 C: [Yeh]
25 N: =you know anything else at ↑all:: then- then by all
26 means give us a call back.
27 C: Ye.
28 N: Yea:h?
29 C: That's lovely.
30 N: Al[right then]
31 C: [Thanks so] much indeed
32 N: Okay bu bye now.
33 C: Bye bye.
34 N: Bye.
----End of Call.

Extract 6.10

MCPAT10/Nurse16, Call-handler initiated closing [17:10 - 19:04].

((Summary: The caller is a female patient with breast cancer. She telephoned the helpline for advice about how to manage mouth ulcers and the call-handler offered verbal suggestions as well as a booklet on *Mouth Care*. Just before this extract the call-handler thought of another booklet which might have been useful for the callers needs called *Dry Mouth*. The "too" from the call-handler's first turn was her informing the caller that she would send the caller this booklet as well)).

1 N: ↑Although what I'll do is if I send you that

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- 2 booklet too .hh u:mm you can have a look >coz you
3 might< get some tips from tha:t.
- 4 C: Um no thas good.
- 5 N: But that's more for people who have had (.) kind of
6 radiother[apy]I mean most of these things tend to=
7 C: [U:m]
8 N: =be: very similar: you know the:[type treatment]=
9 C: [↑Yes of course]
10 N: =for them so you might- .hhh I'll send you that >it
11 might talk about coz you've had radiotherapy in
12 your mouth which you haven't but this is some of
13 the things to do or things to ↑eat so< .hhh=
14 C: =No that's good.
15 N: Er:m just donate the book back when your[:
16 C: [↑Ah that's
17 nice [yeah] I will do
18 N: [()]
19 N: ↑Er::kay.
20 (0.9)
21 N: ↑Akay, so I'll send that and I that'll go out[to=
22 C: [No
23 thanks ((name))
24 N: =you. It shou:ld get it to you before the end of
25 the ↑week hopefully all being-
26 (.)
- ((31 lines omitted. The pair discussed how "hopefully" the caller's ulcers will be better by the time the information reached her. This sequence is touched off by the call handler's turn at line 25 about when the booklet will reach her "hopefully" all being well. This was hearable as all being well subject to the post rather than the caller's recovery within this time)).
- 58 C: But no thanks ((name)) that's- that's great, nice to
59 talk to you.
60 N: No problem.
61 C: £Alright£
62 N: Nice to talk to you too=
63 C: Yea:h. Okay thanks a lot then.
64 N: Okay
65 C: ↑Bye.
66 N: °Thanks((name))° bye now.

----End of call.

The following analysis will focus on four main observations from these extracts.

1. The call-handlers' first turns in all extracts involved a move to a future action and included an offer to send a Macmillan booklet: "And I could put those (series) of booklets in as well for you just to have a look" (extract 6.8, lines 1-2); "I can certainly send you this information like I say" (extract 6.9, lines 2-3); and "Although what I'll do is if I send you that booklet too" (extract 6.10, lines 1-2). The design of these turns showed that the call-handler had already offered to send the caller this information and was retrieving it to finalise the arrangement near closing (Sacks, 1992a). The call-handlers then described the contents of the booklet and how it would meet the patient's informational needs (extract 6.8 and 6.10) or they checked the caller's address (extract 6.9).
2. The design of these offers established an acceptance as the relevant next action and call-handlers appeared to wait for this before producing more closing-implicative moves. For example, the caller in extract 6.8 produced "yeah" as the call-handler was describing the booklet. It looked like the call-handler was about to continue at line 11, "It so (.) .hh maybe", but trailed off upon the caller's acceptance, "no that would be very good" (line 12). It was only then that the call-handler initiated a closing move with "Okay then. .hh And if there is anything else that we can do then obviously don't hesitate to get back to us" (lines 13-14); the first component finalised the arrangement and the second moved toward closure. The caller in extract 6.9 produced "yeah that would be very helpful actually" (line 5) before the call-handler checked the caller's address; and the caller in extract 6.10 produced "no that's good" (line 14) and "no thanks ((name))" (lines 22-3) which showed she would like said booklet.
3. Two of the call-handlers used devices to solicit more uptake from callers with topic-initial elicitors: "Okay then. Anything else at the mome:nt?" (line 19, extract 6.8); and "Was there anything else at all or," (line 14,

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extract 6.9). These turns were placed after the callers receipted the nurses' moves out of closing: in extract 6.8 the caller agreed to the nurse recording the conversation with "Yeah that's not a problem" (line 18); and in extract 6.9 the caller responded to the nurse's informing of when the booklet was likely to arrive with "Nyeah. Probably" (line 13). What is noticeable about these utterances is that they were responsive to the previous action but they did not progress the call forward. Topic-initiators, then, are a way for nurses to gently move the caller toward the relevance of closing by explicitly soliciting further "mentionables". The callers within each extract did not raise additional concerns which might have been related to the fact that they did not have any, or related to late placement of the elicitors and their "no-preferring" design (Heritage *et al.*, 2006; Heritage & Robinson, 2011; Robinson, 2001). Once the warrant was explicitly confirmed, the callers in extracts 6.8 (line 24) and 6.9 (line 31) each went on to produce an appreciation and the participants progressed toward closing. The evidence for topic-initial elicitors as devices for the nurses to solicit more uptake from callers appears in extract 6.10. The call-handler did not produce one of these devices and this was related to the uptake of the caller throughout the sequence and the early production of an appreciation (lines 23-24 and 58 respectively).

4. The nurses also orientated to callers to produce the first terminal utterance. In all extracts there were opportunities for the nurse to say "goodbye" but they produced turns which instead deflected this to the caller: in extract 6.8 the reciprocal appreciation "Oka::y thank you:" (line 25); and the "okay" (line 64) in extract 6.10. The nurse in extract 6.9 did produce the first terminal utterance but only after the caller produced a definitive closing move (line 31).

There was further evidence to suggest that call-handlers used devices to solicit more uptake from callers to make a closing move. The next two examples involved the caller producing a turn which *could* function as a closing move but which did not display an overt readiness to leave compared to appreciations. The call-handlers subsequently offered to send the caller information which ultimately resulted in the caller producing an appreciation.

Extract 6.11

MCPAT27/Nurse13, Soliciting more uptake in call closings [06:41 - 8:45].

- 1 C: ↑Alright
 2 N: Oka:y
 3 C: Yeah huh hu::h [(?)]
 4 N: [Did] you:: em (.) I mean we've go:t
 5 written information abou::t stomach cancer we've got a
 6 bookle:t I could send you ou::t
 7 C: Oh please yeah
 8 N: And um I don't know if you use internet or no::t (.)
 9 u:::m
 10 C: Er I'm a bit hit and miss with it huh huh huh
 11 N: Right er yeah [(?)]
 12 C: [So]
 13 N: Er er w- we (.) we have our own websi::te and u:::m
 14 there's information there on the website as well (.) um
 15 but I can send you out the booklet a:nd,
 16 C: Brilliant
 17 N: If you've got any questio::ns e:::rm or just need
 18 clarification of if you just need someone to talk to cos
 19 i- it's gonna to be a pretty kinda rough time for you
 20 (.) >over the< next few months the::n you've got our
 21 number so give us a call
 22 C: Alright fantastic thank you very much
 23 N: Not at all you're welco::me
 24 C: Okay thank you:
 25 N: Bye:
 26 C: Thanks then bubye,
 ----End of call.

The caller produced a closing move at line 1 with “↑Alright” - the accompanying high intonation marked this as closing implicative (Schegloff & Sacks, 1973) - but it was not as definitive as an appreciation. The nurse aligned to the closing move with “oka:y” but the elongation functioned as a checking device to ensure the caller was ready to leave rather than simply acting as a free turn of talk. The call-handler then offered to send the caller a booklet about stomach cancer. After the arrangement was confirmed (lines 17-21) the caller produced: “Alright fantastic thank you very much” (line 22) - a move which was much more closing-implicative.

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Extract 6.12 is another example that followed this same pattern of a possible closing move and an offer of further information:

Extract 6.12

MCPAT5/Nurse9, Soliciting more uptake in call closings [08:27-10:05].

- 1 C: .hhh So that's about it really. ↑Oh ↑right okay .hh hh
2 N: ↑Would you like me to send out (.) u::m some
3 of our information about >like there's one< avoiding
4 infection when you're on chemotherapy
5 C: ↑Yes. Please=
6 N: =When you're immune system's down a bit .hh[h an: a]lso=
7 C: [↑Yea:h.]
8 N: =and u::m also a booklet on::n lung cancer treatment?
9 (.)
10 C: ↑Yes. please.
11 N: Okay I'll certainly send that out to .hhh [you've-]=
12 C: [.hh ↑And-]
13 N: = you've given your u::m (0.2) your details to my
14 colleague there ((name))?
15 C: Ye I yeah I'm going to- w::ould you like me to go through
16 them again=me address a:::n er me date of birth and,
17 (.)
18 N: Yeah that's fine w- we'll [have] that on t[he computer]=
19 C: [Yeah] [.hh ↑And-]
20 N: =So I'll just send this stuff out to yo[u- your home=]
21 C: [Right .hhh an-]
22 N: =address.
23 C: An- Sorry=do you know of help w- (.) with m- money or b-
24 benefits or things like that, am I- can I get anything
25 (0.5)
26 N: .hhh ↑U::m (.) yea:h I mean that- that might be (.) um::
27 be perfectly possible u:r we have- I'll send you out a
28 booklet called (.) .hh help with the cost of cancer

(18 lines omitted re the call-handler details the contents
of the booklet)).
47 C: ↑O::kay love.
48 N: Or a ↑change in any benefits you know=
49 C: =Yes, yeah. [↑okay we]ll thank you very much for your=

50 N: [And er-]
 51 C: =↑help
 52 N: No bother [no bother at all]
 53 C: [I feel ↑better ↑]now
 54 N: Ah that's grea[t.
 55 C: [↑↑Thank you.
 56 N: Okay take [care
 57 C: [Alright then by::e.
 58 N: Bye now.
 ---- End of call.

The caller's turn (line 1) was closing implicative and *implied* her 'business' was completed, "So that's about it really", and she produced an utterance, "Oh right okay", that displayed she had undergone a change of state to being informed (Heritage, 1984). The components of this latter turn were backward facing and did not include a projection toward the next activity (closing) thus suggesting she was not ready to leave at this particular moment. It is for this reason (i.e. that a warrant for closing had not been explicitly produced) that the nurse then offered to send the caller further information (lines 2-4). The reasons the caller did not move the call toward closing is related to the "mentionable" (Schegloff & Sacks, 1973) about finance she went on to raise during this section. She first attempted to raise this in overlap with the call-handler's arrangement-making (lines 12 and 19) and eventually produced it at line 23. Much later in the sequence the caller provided a more definitive closing move (line 49) which opened the closing section and ultimately resulted in termination.

In summary, there was an orientation by both participants for callers to make the first closing move and this was represented statistically and in the practices call-handlers used to solicit more uptake if a move from the caller was not forthcoming. The closing sections varied in length depending on which participant made the first closing move and this was related to whether a warrant for termination had been created and understood by both speakers. This was usually accomplished with the production of a pro-forma appreciation which may have been upgraded over the course of the closing section and acted as the definitive closing move before terminal exchanges were produced. Now that I have examined how the calls were routinely brought to a close, I will

show how within these closing moves callers expressed differing levels of satisfaction with the services received.

6.3 Part Two: Expressions of Caller Satisfaction

Caller satisfaction, as described in chapter one (see section 1.5, pp. 14-17), has been widely evaluated for the past twenty years, largely through standardised quantitative measures (i.e. data obtained from self-report methods such as postal questionnaires). Findings from this research have shown that callers overwhelmingly report high levels of satisfaction (Slevin *et al.*, 1988; Altman, 1992; Venn *et al.*, 1996; Darrow *et al.*, 1998; Lindgren & Boman, 2003; Reubsaet, Lechner & De Vries, 2006), with this sometimes exceeding 93% (La Porta *et al.*, 2005; Lechner & De Vries, 1996; Montazeri *et al.*, 1999; Dean & Scanlon, 2007; Dean & Ahmed, 2011). The quality of the information obtained and the nurses' communication skills are two factors that best predict caller satisfaction with the calls (Altman, 1992; Lechner & De Vries, 1996; Darrow *et al.*, 1998; Montazeri *et al.*, 1999; Reubsaet, Lechner & De Vries, 2006; Dean & Scanlon, 2007; Dean & Ahmed, 2011). A small number of studies reported that some callers were dissatisfied with the services received (Lechner & De Vries, 1996; Lindgren & Boman, 2003; Reubsaet, Lechner & De Vries, 2006; Dean & Scanlon, 2007; Dean & Ahmed, 2011). In the two studies that enabled callers to write comments about their varying satisfaction, callers indicated they were discontent because the call-handler had been too intent on providing emotional support when their enquiry was about accessing medical information (Dean & Ahmed 2011, p. 27); and another indicated the information was not relevant to their situation (i.e. it was not relevant to their cancer type or treatment) (Lindgren & Boman, 2003). The qualitative evidence base about caller experiences of using cancer helplines is small but one study corroborated these quantitative findings and found that callers were generally positive about their call but some participants also discussed feeling dissatisfied (Ekberg *et al.*, 2014). In terms of the latter group, callers attributed their discontent to the communication skills of the nurse, specifically if the call-handler did not display empathy towards the caller's situation or if they were "too formal" (*ibid*).

The use of quantitative methods to measure patient satisfaction have been widely criticised in healthcare. These criticisms relate to the validity of such

measures, whether they are meaningful and the discrepancies between the level of satisfaction reported in the questionnaire and how the patient actually felt in regards to the services provided during the consultation (Avis, Bond & Arthur, 1997; Williams, 1993; Sitzia & Wood, 1997; Williams, Coyle & Healy, 1998; Gill & White, 2009; see also relevant publications from the IMPROVE study team, Roberts *et al.*, 2014; Burt *et al.*, 2016). Although there is no specific study highlighting these problems in relation to caller satisfaction, such criticisms may be extended to this area based on the similar quantitative techniques employed.

In contrast to self-reported data, conversation analysis examines endogenous indicators of satisfaction as they are expressed *during* the interaction. These indicators can be used to determine if there are certain interactional styles associated with varying expressions of satisfaction (Drew, Chatwin & Collins, 2000; Robinson & Heritage, 2006) and findings can later be turned into quantitative measures (Clayman, *et al.*, 2002; Reuber *et al.*, 2009). Pro-forma appreciations, like the ones discussed in the previous section, are widely used to close telephone service encounters (Clark & French, 1981; Zimmerman, 1992; Zimmerman & Wakin, 1995; Raymond & Zimmerman, 2007; Heritage & Clayman, 2010). There is accumulating evidence to suggest that these displays of gratitude can concurrently display callers' satisfaction or otherwise with the services received as well opening a closing sections (Clark & French, 1981; Zimmerman & Wakin, 1995). Moreover, these routine expressions of appreciation can be calibrated in such a way so that weak expressions are merely used as a pro forma resource for exiting the call, and may thereby not truly express appreciation or satisfaction; whilst strong expressions of gratitude more clearly convey caller satisfaction (Clark & French, 1981; Zimmerman & Wakin, 1995; Heritage & Clayman, 2010). It is the ways in which callers use expressions of gratitude to bring service calls to a close, and in so doing express also their satisfaction with the service provided during the call that the following 'satisfaction work' will be situated (Swan, 1992; Parker, Pomerantz & Fehr, 1995).

I will now examine how callers expressed these differing levels of satisfaction within their closing moves and the consequences this had upon the structure of the closing sections.

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6.3.1 Satisfaction

Callers expressed their satisfaction by upgrading their appreciations into stronger or more enthusiastic displays of gratitude toward the services received, as the following example shows. Just before this extract the participants were talking about travel insurance and whether the patient would need a letter from her GP to explain that she was receiving medical treatment for cancer when she went on holiday. The nurse informed the patient that this would be unnecessary because she was travelling within the UK.

Extract 6.13

MCPAT35/Nurse6, Caller satisfaction [15:40-16:53].

- 1 C: Oh well thank you. ↑Oh it (.) has been nice to talk to you
- 2 N: You're welcome you're welcome. Now I thin- I think you
- 3 gave my colleague your address is that ri:ght
- 4 C: Yes I di:d.
- ((10 lines omitted re the call-handler checks the callers address is correct)).
- 5 N: Yep that's what I've got. That's what I've got
- 6 C: Oh (.) ↑Thank you very mu::ch.
- 7 N: Lovely. Is there anything else that I can help you with
- 8 at all,
- 9 C: I don't think there is thank you::
- 10 N: Oka:y [oka:y]
- 11 C: [It's been] quite comprefhe::nsive£
- 12 [huh huh]
- 13 N: [£Oh r(h)i:(h)ght£] .hhh I'll I'll pop this information in
- 14 the post for you .hh U::m are you happy for me just to
- 15 keep a very brief record of our ca::ll today:?
- 16 C: Yes ce:rtainly.
- 17 N: Is that al[right] it's all confidential within=
- 18 C: [Ye::s]
- 19 N: =the se:rvice but (.) u::m y- you know if you if you ring
- 20 us again then we'll just have a brief record of of what
- 21 I'll I'll cause I'll just note what are the publications
- 22 that [I've sent out to you]
- 23 C: [Oh that's fi::ne.]
- 24 N: So is that alright
- 25 C: Yes thank you:..

26 N: Okay okay and, (.) you know if you want to give us a ring
 27 again then obviously you're welcome to do so we're here
 28 nine till eight (.) Monday to Fri:day
 29 C: Ri::ght. ↑Thank you very much
 30 N: £Alri::ght then£ ((name))
 31 C: .hh ↑Bye then
 32 N: Okay bye bye:
 ----End of Call.

The patient first opened the closing section with an appreciation, “Oh well thank you”, and a positive assessment, “↑Oh it has been nice to talk to you” (line 1). The first component moved beyond the routine appreciation with the preface “Oh” (Heritage, 1984) which the caller used repeatedly throughout the closing section to emphasise the appreciative action of the turn. This constructed the call as a positive experience based on the behaviour of the call-handler because it was personalised for this *particular* call-handler rather than call-handlers or the services received in general (i.e. with the more routine, “thank you for your help”). The personalised nature of this call was further represented in the behaviour of the participants at lines 11-13. The caller appeared to make a joke that the information provided by the call-handler was “quite comprehensive”, delivered with smile voice to show the light-hearted nature of the comment. The call-handler responded with laughter (line 13) and thus her understanding of the turn as a joke. Finally, the call-handler used the caller’s name shortly before termination, again through smile voice (line 30), reciprocating the personalised tone constructed by the caller. All of these features suggest the pair had developed a rapport over the phone and went beyond the formality usually associated with service encounters.

The next caller also exhibited a high degree of satisfaction both in her pre-closing moves and over the course of the closing section (this closing first appeared on p. 153-4). The caller is a female terminal lung cancer patient who requested information about treatment, specifically about how long one of her cancer drugs would take to leave her system (she was going on holiday and was concerned she would be unable to go due to her treatment). Prior to the closing, the nurse informed the caller that her drugs would only take a couple of days to leave her system so once she stopped taking them she would be able to go on holiday.

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Extract 6.14

MCPAT5/Nurse9, Caller Satisfaction, [08:31-10:13].

1 C: So that's about it really. ↑Oh ↑righ:t okay .hhh[h
2 N: [↑Would
3 you like me to sen:d out (.)u::m some of our information
4 about >like there's one< a↑voiding infection
5 when you're on chemotherapy=
6 C: =Yes please=
7 N: =When you're immune system's down a bit .hh[h an: a]lso=
8 C: [↑Yea:h.]
9 N: =and u::m also a booklet on::n lung cancer treatment?
10 (.)
11 C: ↑Yes. Please.
12 N: Okay I'll certainly send that out to .hhh y[ou've=
13 C: [.hh ↑And

(26 lines omitted re the caller raises ask finance
related question and the call-handler responds with an
offer of a booklet about this topic)).
14 C: ↑O::kay love.
15 N: Or a change in any benefits you know=
16 C: =Yes, yeah. [Okay we]ll thank you very much for your
17 N: [And er-]
18 C: =↑help:
19 N: No bother [no bother at all
20 C: [I feel ↑better ↑now]
21 N: Ah that's grea[t.
22 C: [↑Thank you.
23 N: Okay take [care]
24 C: [Alright] then by::e.
25 N: Bye now.
----End of call.

The caller produced a term of endearment at line 41, “Okay love”, an upgraded appreciation, “thank you very much for your help”, and finally a positive assessment, “I feel better now”; all of which delivered through heightened intonation to display her satisfaction (Schegloff, 1986). The reference to the caller’s feelings and the use of “now” constructed the caller as being in a positive state *now* she telephoned the helpline compared to how she felt

before. The nurse produced the reciprocal, “ah that’s great” (line 21), which was similarly positive in its design before the pair moved toward termination.

The caller in this final example, the daughter of a male patient, was concerned about visiting her father in hospital because she recently had a friend over who was a known carrier of MRSA²⁴. The nurse informed the caller that as long as she carried out all the usual safety procedures in hospital then the patient should not have been at any extra risk of infection.

Extract 6.15

MCREL5/Nurse9, Caller satisfaction [02:10 – 03:08].

- 1 N: So going to visit your da:d and carrying out the normal
 2 infection contro:l procedures,
 3 C: Lovely.
 4 N: He shouldn’t be at any extra risk at all. =
 5 C: =↑Thank you ever so much for all your he:lp.
 6 N: O:[kay]
 7 C: [Tha]nk you for putting my mind at rest h heh.
 8 N: £Your welcome£
 9 C: Thank you.
 10 N: Okay b[ye.
 11 C: [By:e.
 ----End of call.

The extract follows the pattern so far of callers using upgraded appreciations to express their satisfaction, here the emphasis on the “thank” of thank you and on the “ever” of ever so much both marked the work of the call-handler as leading to her positive feeling. The caller then explicitly referenced what the call-handler did for her, “thank you for putting my mind at rest” (line 7), which had a tagged laughter particle at the end. The idiomatic expression conveyed how the caller felt prior to making the call and the tagged laughter was possibly a way for the caller to show she was “relieved” to hear what the call-

²⁴ MRSA stands for Methicillin-Resistant Staphylococcus Aureus. It is a type of bacteria that is resistant to a number of antibiotics and is sometimes referred to as a ‘superbug’. This bug would cause severe harm to a patient with cancer because their immune system would be compromised due to invasive cancer treatments. It would also cause havoc if multiple patients contracted this in hospital. Both of these aspects were likely fuelling the caller’s concern.

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handler said; that she had perhaps been worrying about the problem for a period of time and now has information she was hoping for.

In summary, callers displayed their satisfaction with the information, advice or reassurance they had been given during the call through a variety of upgraded forms of appreciation which they used to bring the calls to a close. One particular means of upgrading their appreciation was to ‘personalise’ the appreciation, by referring directly either to the assistance that the nurse had given (e.g. “↑Thank you ever so much for your he:lp”) (extract 6.14) or to the caller’s feelings or peace of mind (“putting my mind at rest”) (extract 6.15). In some cases, additional features such as positive assessments and laughter also worked to show a positive stance and signalled how they felt about their call experience. It is noteworthy that whenever callers initiated moves of this kind, the calls were brought to a speedy termination. This is in contrast to what happened in other cases in which callers did not produce upgraded appreciation forms.

6.3.2 Dissatisfaction

In a minority the calls, there was evidence that callers were less than satisfied with the service(s) received during the call. These expressions were more implicit than displays of satisfaction and often involved the callers downgrading, both through design and prosody, their expression of gratitude. The caller in extract 16, for example, used the downgraded “alright then” to open the closing section, a much weaker version of ‘thank you’. This caller, a female patient with breast cancer, was concerned about her troubling symptoms and wanted to know if they were related to chemotherapy or if she had something else wrong and needed to see a doctor (this extract first appeared in Chapter 4, p. 86). Throughout the call the nurse repeatedly advised the caller to visit her GP, something she does again here (see line 3).

Extract 6.16

MCPAT9/Nurse3, Caller dissatisfaction [5:10-5:41].

1 N: Er: :m,
2 (0.5)
3 N: Oka:y? .hh[h Start with] your gee pee first=
4 C: [Alright then]
5 N: =because you know it may just be related to the side

6 effects of treatment but I think you should get that
 7 checked out in case you've got one of these nasty
 8 infections that's around.
 9 (0.2)
 10 C: A↓right then.
 11 N: Okay Sarah?
 12 C: Right tha[nks for your help]
 13 N: [Okay you take] care I hope you feel a bit
 14 better oka[y?
 15 C: [Ye- thank you.=
 16 N: =Oka:y bubye.
 17 (.)
 18 C: Bye.
 ----End of call

The caller first acknowledged the nurse's recommendation with "alright then" (line 4) – a turn that did not say whether she would act upon this advice or whether she found it useful (i.e. it is a very minimal). She used this again to open the closing section (line 10), then moved more directly towards closing by upgrading her response to what was at least – but only – a pro forma appreciation *thanks for your help* (line 12). Furthermore, this was prefaced with "right" and with the flat prosody, conveyed an audibly unenthusiastic appreciation (something she repeated in a reduced form in line 15). Moreover, the caller only 'upgraded' to these pro forma appreciations after some pursuit by the nurse (lines 5-8, 11, 13-14) (Raymond & Zimmerman, 2007).

Implicit indications of caller dissatisfaction are clearer in this next example. The caller, a female patient with breast cancer, was concerned about a pain in her leg which she thought could be indicative of cancer recurrence. The start of this extract begins with the nurse repeating advice that the caller should consult her own doctor (lines 1-5).

Extract 6.17

MCPAT13/Nurse8, Caller dissatisfaction [8:41 - 9:43].

1 N: ↑E::::m, (0.3) you know and it's the only way
 2 you're going to find out is is is by maybe going
 3 alon::g going alo:ng to the the the docto:r.=I think y
 4 (you're a) I think you know tha::t. And its n- .hh you

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5 kn[ow I
6 C: [Okay then.
7 N: .tck O:ka::y, [(name) I'm sorry] I can't help=
8 C: [Thank you for talking to me,]
9 N: you any other way .HHH
10 C: That's oka:y.
11 N: .tch ↓O::ka::y [al-
12 C: [Bu'bye:.
13 N: Oka:y ((name)). ((name)) are you happy for me to keep a
14 wee note of our conversation?
15 C: Yea::h, that's o[kay.
16 N: [Okay. And you know we're here. You know
17 we' [re here.]
18 C: [Ye::ah.]
19 N: .hhh U:::m >but you know but i:t's< it was an early
20 cancer that you ha::d, (.) and you've had y- your
21 you had have ju- just remember tha:t it's: been an early
22 ↑cancer an- an you've ha:::d your you're your t:- you had
23 it taken awa::y and you've had your(?) .HH (.) what they
24 call: you know wh- look in (tu::nes)going about bout- you
25 know your Tamoxifen,
26 C: ~Yeah~,
27 N: A back up t- to go round bu- but at the same ti:me .hh you
28 know if you've had this pain for as lo::ng as you've ha:d
29 it, .hh y- you would be best going along to the doctor and
30 just to get it checked out.
31 (0.3)
32 C: Okay then.
33 N: .tck Oka:::y ° ((name)) °?
34 C: Bu'bye,
35 N: Oka:y, you take care bu'by[e.
36 C: [Bye.
 ---- End of Call.

The caller's initial response to the nurse's closing move was a simple acknowledgement, "Okay then." (line 6) similar to the "alright then" used by the caller in extract 6.17. It is clear from the nurse's apology in lines 7-9 that she was aware that she had been unable to answer the caller's enquiry in the way the caller was hoping (recall in chapter 4 that concerns about troubling symptoms are outside the nurses' expertise to handle). From there the caller

moved straight to closing the call with her farewell (line 7). However, the nurse reopened the conversation by attempting to reassure the caller (lines 19-28) and renewed her advice to see her own doctor (line 29-30) – to all of which the caller responded only minimally with an acknowledgement (line 30) and then hastily exited from the call (lines 34 and 36). All of these properties of the caller’s turns in this call closing – her ‘reduced’ pro forma appreciation in line 8 (note that the caller thanks the nurse *for talking to me*, not for any help given), direct moves to exit the call, the prosodically flat character of her turns, and most significantly the absence of any subsequent upgrading of her acknowledgements/appreciation – all exhibited the caller’s dissatisfaction with the services the nurse had provided.

The caller in the final example, a patient with bowel cancer, exhibited similarities to extract 6.17 in that she responded to the nurse’s advice by moving hastily and unilaterally towards call closure. This patient was concerned about a pain in her abdomen after a recent operation.

Extract 6.18

MCPAT4/Nurse8, Caller dissatisfaction [15:23 – 16:42].

- 1 N: So that may be:: (.) that may be the reason for it
 2 so:: I think maybe you’ve you you know if-
 3 [.hh y- y-
 4 C: [I musn’t do anything n[:ow] I’ve got to sit here and=
 5 N: [No:..]
 6 C: =look pretty have I:
 7 N: .hh Do yer- you can do do do y- y- your dustin. Do your
 8 dustin. Your you- no::t anythin’ high u:p. J[ust] do=
 9 C: [No.]
 10 N: =your dustin’. >because< .hhh get somebody else to do your
 11 floo:r a- and do ye hooverin’ for ye.=
 12 C: =Yea[h.
 13 N: [.hhh hhhO:ka::y
 14 C: Okay then thank you:.
 15 N: Oka::y you’re welcome.
 16 C: Thank you (b)
 17 N: Okay ((name)).H[H ((name)]before you go: are you happy=
 18 C: [Okay then.]
 19 N: =for me just to keep a very brief summary of our

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20 conversation?=
21 C: =Ye:::s you can do.
22 N: Okay. Okay. .hh you take things easy.
23 C: Okay then.
24 N: Oka::y you're still recoverin' fr- from your operation.
25 C: Yea:h. But you don't think I've done any- any permanent
26 damage (of it[/or anythin'.])
27 N: [I- I- I do:n't] think so but what I would
28 sa::y is tha #I::# I can't s-=as I say it sounds as
29 though you're maybe doin' too much and maybe strai:ned
30 yourself .hhh
31 C: Yep.
32 N: But it's your it's your gee pee who would be able to say
33 for definite because he would be able to exa:mine you. .hh
34 C: O[kay.
35 N: [You know I ca::n't j'you know I've [I:
36 C: [No I know definitely
37 b[ut you sort of u:m.] (g[ot six months)
38 N: [Yea::h. Yeah.] [(So/Yer) just need t- see if it
39 ca:lms dow:n (.) and if it doesn't you can see your gee
40 pee.
41 (.)
42 C: Okay then.
43 N: O:ka:::y?
44 C: Yeah. Thank you:.
45 N: Oka::y ((name)) you take care:.
46 C: Okay then.
47 N: Oka:[:::y] by:e
48 C: [Bu bye.]
---- End of Call.

It is clear that in response to the nurse's closing implicative summary in lines 4 and 6 that the caller's ironic formulation of the upshot (Beach, 1993) of the nurse's advice, "I musn't do anything n:ow I got to sit here and look pretty have I:" (lines 3 and 5), was less than happy with recommendations provided by the nurse during the call. When the nurse subsequently moved closer towards closing the call with her enquiring "O:ka::y" (line 13), the caller seemed in a hurry to get off the line. She acknowledged the nurse's prior turn only minimally (line 14) and did the briefest pro forma appreciation, "thank you" (lines 14). Her repeat appreciation in line 16 was only that, a straight repeat

without any form of upgrading. So the expression of dissatisfaction conveyed in her ironic response to the nurse's advice was confirmed in her minimal appreciations and haste to end the call.

A feature of these examples was that the call-handlers apparently oriented to the indications that callers were not (yet) satisfied with the information or advice they had been given. Moreover, the call-handler's awareness that the caller was not yet convinced that the information or advice had been sufficient was manifest in their re-opening topics which perhaps were pursuing a more explicit acknowledgement and appreciation of the information or advice provided. However, it was evident that in these extracts the calls closed without the callers having expressed their appreciation or gratitude to the call handler; in this way, callers implicitly displayed their lack of satisfaction with the service provided in the call.

6.4 Conclusion

In this chapter I examined the practices for bringing the cancer calls to a close and how within these closing moves callers expressed differing levels of satisfaction with the service(s) received; two matters that have not been empirically explored in relation to helpline interactions. The main findings from this research include: 1) Closings were overwhelmingly opened by callers with an appreciation (*thank you/very much/indeed/for your help*), which displayed a sense of gratitude towards the services received. They worked as closing moves because the caller showed that their 'business' had been attended to by 'appreciating' the services rendered during the interaction (Clark & French, 1981; Zimmerman, 1992; Heritage & Clayman, 2010). When these moves were produced, the participants progressed swiftly towards termination. 2) Call-handlers' opened closings with offers to send callers a Macmillan booklet which were similarly structured to arrangement-making in both ordinary social and institutional settings (Button, 1987; Sacks, 1992a; Robinson, 2001). Call-handlers also used techniques to solicit more uptake from callers to ensure a 'warrant' for termination had been created and understood by both participants (Schegloff & Sacks, 1973). This usually resulted in the eventual production of an appreciation and this acted as the definitive closing move and the calls ended. And 3) Callers sometimes designed their closing moves in ways which expressed varying levels of

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satisfaction with the services received. Endogenous indicators of satisfaction included: upgraded appreciations (e.g. from *thank you to thank you very much*), positive assessments, laughter, and enthusiastic prosody. Indicators of dissatisfaction included: downgraded appreciations (e.g. *alright then*) and flat, unenthusiastic prosody. Participants displayed their orientation to these different displays, especially expressions of dissatisfaction, as nurses often re-opened previous information and advice-giving sequences, and callers attempted to move hastily and unilaterally towards call closure. The finding that appreciations can be used strategically as well as to close calls builds on analyses of closing practices in other settings (Clark & French, 1981; Zimmerman & Wakin, 1995; Raymond & Zimmerman, 2007; Heritage & Clayman, 2010).

While I proposed an alternative means for exploring caller satisfaction to self-report or survey-based measurements, it should be noted that these displays cannot be taken as definitive proof of caller satisfaction (as findings produced using the former methods cannot be conclusive either). But, indicators of satisfaction or otherwise produced during the calls themselves do help feedback to call-handlers the extent to which they had satisfied the caller's expectations. Such findings might be welcome to healthcare professionals providing services over the telephone who often state that a difficulty of their work is knowing whether the caller had been 'helped' from the information or advice they provided during the call (Leydon *et al.*, in preparation).

Chapter 7: Discussion and Conclusion

7.1 Introduction

This research conducted a conversation-analytic examination of a large collection (n=99) of audio-recorded helpline calls with an aim to understand *how* various medically-related problems were discussed by nurses and those affected by cancer on a leading helpline in the UK called Macmillan Cancer Support (MCS). The rationale for this qualitative investigation was threefold and based on: 1) the recognition that information and communication play an important role in supporting cancer patients and their families through different stages of their illness; 2) the increasing use of cancer helplines to obtain this support; and 3) the overuse of quantitative methods in the existing literature which have largely ignored the interactional process of seeking and delivering telephone-based cancer support, despite the well-known communication difficulties associated with talking about cancer and helpline work more generally.

This study used observational methods and conducted systematic analyses in order to open the 'black box' of cancer helpline communication. Analytic findings were generated inductively based on the communicative conduct of the participants, but were guided by the following research questions:

1. What problems are brought to cancer helplines and how are they sought?
2. What types of care do call-handlers provide and how are they delivered?
3. If communication difficulties associated with helpline work arise during the calls, what are they, and how are they managed by the participants?

In the following paragraphs I will first address these research questions in relation to the main findings of this thesis. I will then discuss the contributions of this work in relation to the study of medical helplines and its implications for helpline practice. Finally, I will evaluate the strengths and limitations of my approach and suggest areas for future research.

7.2 Summary of the Main Findings

7.2.1 What problems are brought to cancer helplines and how are they sought?

The quantitative overview described in **Chapter 3** provided in-depth understandings about caller problems, the types of assistance they requested, and the stage of the patient's illness informing the callers help-seeking behaviour. These findings were generated from a coding framework I developed from my inductive examination of the calls. This framework was refined over the course of my PhD research in order to capture caller problems as they were discussed throughout the calls rather than just the caller's reason for calling as with previous research. Callers telephoned Macmillan to enquire about a range of medically-related matters including information and advice about treatment, current symptoms, uncertain future matters and medical information. Callers generally brought two or more concerns to discuss and some of their requests were outside the remit of services on offer from the helpline.

In **Chapters 4 and 5** I addressed the second aspect of this research question and examined *how* callers requested telephone-based cancer support. In Chapter 4 I described the interactional resources used by callers to construct medical problems to a nurse. Caller problem presentations were structured using three main components: 1) a medical history; 2) a problem construction; and 3) a request for information, advice or support. The latter two components were particularly useful for understanding caller motivations for seeking professional assistance from a *helpline* rather than another healthcare professional or a friend/relative within their social circle. I then examined a collection of problem presentations involving requests for information and advice about the patient's current symptoms. The focus on language use and social action revealed several key patterns within these presentations including: most callers telephoned the service to express their concern about the severity of the patient's current symptoms and asked the nurses to evaluate the extent of the problem (e.g. to diagnose what the symptoms represented or to confirm if the patient needed to see a doctor). A smaller proportion of callers requested symptom management advice and explained

that the patient had tried (and failed) to alleviate the symptom prior to contacting the helpline but it had persisted and was still causing a lot of discomfort or pain. Finally, patients and carers predominantly used extreme case formulations (Pomerantz, 1986) to describe the patient's symptoms which conveyed: a) their severity to a recipient who did not have visual access to the problem being described; and b) how the caller knew the symptoms were different and thus a cause for concern compared to the other symptoms experienced over the course of the patient's illness.

In Chapter 5 I built upon this analysis and examined how callers formulated requests for a prognosis. This analysis examined requests made during the opening moments of the calls as well as concerns that were volunteered as multiple issues. Callers frequently requested a prognosis in a direct way, using language associated with estimated timelines (e.g. prognosis, life expectancy and length of life). The design of these turns projected a 'timeline' as the relevant next action which had implications upon how the nurses managed these requests.

7.2.2 What types of care do call-handlers provide and how are they delivered?

The second aspect of the quantitative overview described in Chapter 3 coded the ways in which call-handlers frequently responded to caller requests. These responses fitted into three broad categories of information, advice and psychosocial support and each heading included more details about the specific action performed. Nurses were most likely to provide verbal information (86.9%), refer callers to other healthcare professionals (64.6%) and offer callers a Macmillan booklet or factsheet (37.4%). These findings are related to the mission statement of the helpline which describes the service as an *information support line*; and also to the concerns that were outside the remit of the nurses' expertise (i.e. the caller needed to be signposted to another service or healthcare professional). There were some slight differences in the way these calls were handled depending on whether the caller was a patient or somebody calling on behalf of a patient (such as a relative, friend or partner). Patients, for example, were offered booklets (45.3%) more frequently

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than carers (28.3%) and received more medical advice (24.5% to 15.2%); and carers received more emotional support (26.1% to 15.1%).

7.2.3 If communication difficulties associated with helpline work arise during the calls, what are they, and how are they managed by the participants?

The communication difficulties associated with helpline work predominantly arose when the caller's request was outside the remit of the call-handlers' expertise. The symptom concerns described in Chapter 4 were one class of concerns that could cause problems for the participants over the course of the interaction because the nurses did not have the resources available to diagnose the patient's symptoms over the telephone. Requests for a prognosis were also difficult for the nurses to discuss for the similar reason that they did not have the information, expertise or resources to deliver prognoses for callers/patients over the telephone.

In Chapter 5 I conducted a detailed analysis of nurse responses to prognosis requests. Nurses displayed their orientation to 'difficulty' which was evident in the content of their responses (repetition, conflicting pieces of information and advice, misalignments between the participants) as well as how the information was delivered (speech perturbation, pauses and lip smacks). I explored the reasons for this interactional trouble and theorised it was related to the ordering of discrete steps within the nurses' responses. These steps included: techniques to manage the callers' expectations, advice to speak with a medical professional involved in the patient's care, and the prognostic-information delivered. I argued that it was important for nurses to construct the problem as 'doctorable' early on in the sequence and to only provide general information about prognoses (e.g. the five-year survival rate) rather than specific information about patients and their cancer types.

Whilst the nurses did everything they could to assist callers with their problems, sometimes they could not meet their expectations. In these cases, such as concerns about troubling symptoms and prognosis requests, the matter of whether the caller had been 'helped' became a real-time issue for the

participants during the calls. This had implications upon how the calls were brought to a close which I discussed in Chapter 6.

Callers routinely opened a closing section with the pro-forma appreciation, *thank you for your help*. This turn created a ‘warrant’ for closing the call as it displayed the caller’s readiness to leave and when produced the participants progressed onto call termination in few turns. The design of these appreciations could concurrently display the callers’ satisfaction or otherwise with the services received during the call (Clark & French, 1981; Zimmerman & Wakin, 1995; Heritage & Clayman, 2010). Indicators of satisfaction included: enthusiastic prosody, upgraded appreciations (e.g. *thank you very much for your help*), positive assessments (*I feel better now*) and personalised displays of gratitude for the call-handler (*Oh it has been nice to talk to you*). Displays of dissatisfaction included: downgraded appreciations (*Okay/alright then*) and flat, unenthusiastic prosody. The latter indicators often resulted in the nurses repeating information and advice provided in the main body of the call and thus displayed their awareness that a ‘warrant’ for termination had not been created and thus, that the callers’ expectations had not (yet) been fulfilled.

7.3 Contributions and Implications of this Research

7.3.1 ...for the study of medical communication and helpline interactions

The coding framework described in Chapter 3 provided new and in-depth understandings about the problems informing caller reasons to seek assistance from this helpline as well as the types of assistance associated with providing cancer care over the telephone. These understandings were achieved by *inductively* coding ‘real-time’ audio recorded helpline calls rather than relying on in-service evaluation forms or caller questionnaires as with previous quantitative helpline research. An implication of this coding work suggests that future research should also incorporate observational data into their research design in order to generate more detailed findings about caller problems as they are volunteered throughout the calls. Existing research about the types of problems presented to cancer helplines applies to the problem presented in the opening phase only. Indeed, conversation-analytic examinations of helpline

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calls have similarly focussed their quantitative descriptions on caller 'reasons for calling' rather than how (if) multiple issues were volunteered throughout the calls (Potter & Hepburn, 2003; Edwards & Stokoe, 2007; Shaw & Kitzinger, 2007; Butler *et al.* 2009). Detailed analyses about caller problems and frequent nurse responses are useful in terms of contextualising the communicative conduct of the participants before detailed analyses examine specific practices for seeking and delivering assistance. Moreover, the findings from such analyses may be useful for helpline organisations in terms of understanding how their services are being used and areas they may need to improve upon (e.g. by offering more training to helpline staff); as well as the call-handlers fielding these calls in terms of preparing for the multiple questions/concerns that could be made over the course of a single call.

The analysis of caller problem presentations in Chapter 4 contributed new understandings about how callers constructed medically-related problems to cancer helpline nurses. Macmillan places great emphasis upon people using their service for whatever reasons they choose, even if that reason is to simply chat about their current situation. However, as my analysis showed, callers typically orientated to a 'problem' they needed help resolving which is similar to findings from other CA examinations about how callers request assistance from professional organisations (Sacks, 1967; Potter & Hepburn, 2003; Edwards & Stokoe, 2007; Shaw & Kitzinger, 2007). The second part of this chapter described the interactional resources callers used to present troubling symptoms arising from the patient's diagnosis. Existing research had overwhelmingly focussed on primary care doctor-patient interactions and the construction of *acute* medical problems rather than how symptoms arising from an a *serious* 'known medical problem' were constructed (Heath, 2002; Robinson & Heritage, 2005; Halkowski, 2006; Heritage & Robinson, 2006a; Heritage & Clayman, 2010; Lee & Kim, 2015). Moreover, this analysis revealed more about the type of assistance people affected by cancer require in regards to current symptoms. So, rather than labelling caller requests as 'wanted information about current symptoms' / 'side effects' as with descriptions in the current literature (Sanson-Fisher *et al.*, 2000; Harrison *et al.*, 2009; Clinton-McHarg *et al.*, 2014) and clinical guidelines (DoH, 2014), these findings showed more precisely what these callers needed in regards to troubling symptoms.

Findings from Chapter 5 provided empirical evidence about how requests for a prognosis requests were formulated and managed on the telephone. Conversations about what might happen to a patient over the course of their illness had been labelled as 'sensitive' and 'difficult' for participants of face-to-face doctor-patient interactions (Silverman & Peräkylä, 1990; Silverman, 1997; Rodriguez *et al.*, 2007; Rodriguez *et al.*, 2008; Parry, Land & Seymour, 2014), but discussions involving prognoses *specifically* had not been previously examined. This analysis showed that the nurses displayed an orientation to these discussions as 'difficult' more so than callers as the latter overwhelmingly requested a prognosis in a direct way and sometimes as their reason for calling (rather than building up to these requests over the course of the interaction as is usually the case with 'sensitive' topics – see Schegloff & Sacks, 1973). This analysis also provided new understandings about how call-handlers managed requests that were outside the remit of their expertise - a challenging aspect of helpline work identified in qualitative study about the same helpline (Leydon *et al.*, in preparation). Previous research about the challenges associated with helpline work predominantly focussed on distressed callers (Hepburn & Potter, 2007; Hepburn & Potter, 2010; Shaw & Kitzinger, 2013) rather than the difficulties that could arise subtly across a wider range of calls.

Finally, Chapter 6 provided new understandings about how these helpline calls were brought to a close – previous research had focussed on ordinary social telephone calls (Schegloff & Sacks, 1973; Button, 1987; Sacks, 1992a; Patterson & Potter, 2009) and other institutional interactions such as doctor-patient interactions and calls to the emergency services (Clark & French, 1981; Robinson, 2001; West, 2006; Zimmerman & Wakin, 1995). Perhaps most importantly, though, this analysis showed how caller satisfaction could be measured endogenously rather than using self-reported data. The finding that displays of satisfaction arise in closing environments could be useful for call-handlers, in terms of understanding whether they have fulfilled the callers' expectations; as well as researchers investigating other institutional interactions (e.g. primary care consultations) to examine if indicators of patient satisfaction arise in the closing phase of these interactions too. This could offer an alternative to relying on questionnaires to measure patient/caller

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satisfaction as they have repeatedly been shown to be inaccurate or lacking in meaning (Williams, 1993; Avis, Bond & Arthur, 1997; Sitzia & Wood, 1997; Williams, Coyle & Healy, 1998; Gill & White, 2009).

7.3.2 ...for helpline practice

The use of audio-recorded 'real-time' helpline calls opposed to self-reported data means that findings from this research could have implications for training helpline staff in the future. In particular, the detailed examination of prognosis discussions and call closings could be used as exemplars to highlight why the participants encountered interactional trouble and the ways in which this could be avoided.

7.4 Strengths and Limitations of the Research

This conversation-analytic examination of cancer helpline talk offered an alternative perspective to existing quantitative helpline research and identified several key aspects about the inner-workings of helpline communication. My four empirical chapters highlighted how different forms of telephone-based support were solicited and delivered, and how certain difficulties associated with talking about cancer and helpline work were orientated to by the participants during the calls. The large amount of calls ensured the practices identified were reflective of how these interactions routinely unfolded rather than reflecting idiosyncrasies of a limited number of participants. This thesis was nested in a broader programme of research that aimed to understand the role of cancer helplines in the UK. Findings from this broader research, especially the work conducted in the qualitative work stream (Ekberg *et al.*, 2014; Leydon *et al.*, in preparation), enabled me to contextualise the conversational practices identified within my analyses with views of call-handlers about challenging aspects of their work as well as the reasons callers use these services. Furthermore, early work by the helpline research team (Leydon, Ekberg & Drew, 2013; Leydon *et al.*, 2013) showed that findings from CA could be used to train helpline practitioners in a feasible and acceptable way. This is promising for some of the findings generated from this thesis (especially those from Chapters 5 and 6).

However, while there are many strengths to the design of this research there are also some limitations that should be acknowledged here. The first apply to

the findings generated from two of my empirical chapters. In Chapter 3 I described a framework I used to code caller problems and nurse responses. However, while this framework was discussed in supervisory team meetings, it has not (yet) been formally tested by other researchers. A sample of calls alongside my categorisation of caller problems and nurse responses would need to be tested in order to examine if this is a reliable method for coding these helpline calls before findings from this chapter can be published. In Chapter 6 I discussed how caller satisfaction could be measured endogenously by examining the ways in which callers expressed their satisfaction or otherwise during the calls. However, the practices I associated with expressions of 'satisfaction' and 'dissatisfaction' cannot be considered as concrete evidence that the callers were content with the outcome of their calls. More research needs to be conducted in order to further understand these expressions.

The second limitation of this thesis is that the findings apply to the inner-workings of *one* cancer helpline only. Further research is needed in order to understand if the problems/challenges identified within this thesis are generalisable to other medical helplines. A recent paper by Hepburn, Wilkinson and Butler (2014) identified several cross-cutting themes within the study of helpline communication including: 1) the giving, receiving and resistance of advice; 2) the expression of strong emotion and management in coordination with helpline goals; and 3) how the policies of the helpline shape the interactions between the callers and call-handlers. This paper demonstrates that findings from conversation-analytic examinations can be synthesised in order to offer broader understandings about the interactional practices for requesting and delivering telephone-based assistance across different helplines. However, the practices identified within this thesis need further investigation and compared with other medical helplines before such understandings or broader practice recommendations can be generated.

The third limitation of this research is that it is topically restricted to certain aspects of the calls. Conversation analytic research requires the systematic and detailed exploration of social interaction which is achieved by repeatedly listening to data, meticulous transcription and thorough analysis of certain conversational practices. This type of research is labour-intensive and the focus

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of analyses over a three-year period are necessarily constrained. This means that the sampling decisions and focus for each chapter excluded other topics and therefore do not represent all there is to say about the inner-workings of this cancer helpline. Other topics such as how this form of support is requested and provided more generally, caller complaints and the delivery/receipt of emotional support were not examined (but could have revealed more about how the helpline was being used/operated).

The fourth limitation of my thesis is that the data may now be considered out of date as it was collected in 2010. Macmillan is the leading cancer charity in the UK and is constantly innovating the way it delivers information and support to those affected by cancer. Within the time period of this research, the helpline was in the process of changing various aspects of their call management. These included: removing the data collection phase of the ISO calls so callers could be triaged to a nurse or a member of the welfare rights and benefits team in less time; changing the questions within this phase so that the callers' ethnicity was solicited at certain months of the year rather than every call; and providing more training for frontline call-handlers about how to enquire about the caller's psychosocial well-being. While my findings are reflective of what happened within the calls at the time the data was collected, future researchers should be aware that medical helplines frequently undergo organisational changes that may alter the phase-structure of the interaction (and so any findings they generated about this).

Finally, although findings from the broader helpline research resulted in recommendations for training helpline staff (Leydon, Ekberg & Drew, 2013; Leydon *et al.*, 2013), my research has not (yet) had a practical impact upon call-handling practice. This was related to the frequent staff changeovers that occurred within the time period for this research (as described above), but also due to the large amount of calls analysed for this thesis. The analysis phase of this research was thus more time-consuming than previously anticipated and so my findings are largely descriptive.

These limitations notwithstanding, this thesis provided an in-depth understanding about cancer helpline talk which could be developed with

similar qualitative explorations in the future. In the penultimate section I will offer recommendations about what these explorations could be.

7.5 Recommendations for Future Research

One important future direction would be to collect more data from Macmillan, or another cancer helpline, to develop findings from this thesis. This would ensure that the research is reflective of the helpline's current practice and may reveal additional insights that were not apparent within the sample used for this study. For example, prognosis requests were relatively under-represented in the corpus, as were discussions about other future matters such as fears of cancer recurrence and end of life. The requests I did analyse were slightly skewed towards direct requests for a prognosis, but there were enough implicit turn designs to suggest that the requests may actually be distributed more evenly. With more data, future research could either continue with my analytic focus about how prognosis requests are designed and if the call-handlers encounter difficulties during such discussions; or expand the focus and examine the features of 'future talk' more generally (i.e. with cancer recurrence, illness progression and end of life included within the same collection). With the latter focus, a sufficient amount of nurse calls would need to be collected to ensure that each future topic was evenly distributed within the sample.

Findings about the caller requests for assistance could be used to inform a topic guide in future qualitative research. For example, a significant proportion of callers telephoned the helpline to express their concern about the patient's current symptoms rather than visiting the patient's GP or another NHS service such as the 111 health information hotline. Both of these services are more equipped for evaluating troubling symptoms yet the callers clearly sought this kind of help from Macmillan Cancer Support's helpline service. Some callers described their reasoning for telephoning the helpline and explained that they could not get in touch with the patient's GP or that the symptoms had developed suddenly (e.g. overnight) and they wanted assistance immediately. A qualitative interview study could follow up on these preliminary themes and further investigate caller motivations for using the helpline. This would provide more understandings about the help-seeking behaviours of those affected by cancer.

Chapter 7

A significant finding from this research was about endogenous measures of caller satisfaction. Knowledge of these indicators could be useful for call-handlers fielding such calls in terms of understanding whether the callers' expectations had (likely) been met, as well as providing helpline organisations with a useful tool to train to their staff. However, future research first needs to disentangle whether satisfaction displays are related to a communicative event that occurred during the calls (e.g. repetition of advice previously resisted, an offer to send a Macmillan booklet, etc.), or associated with certain outcomes (e.g. good news, recommendations to visit other healthcare professionals, etc.) before any practical recommendations could be developed. My notes at the time of conducting this work noticed that expressions of dissatisfaction were associated with misunderstandings between the participants about the callers' 'reason for calling' - particularly if the caller was seeking reassurance and the nurse responded with something other than reassurance such as practical advice. While this theory needs to be systematically explored, ideally with more cases, it does offer preliminary evidence to suggest that caller dissatisfaction is related to a local communicative event.

Another important area of future research would be to compare the inner-workings of these cancer calls with other medical helplines. For example, this research identified certain requests that were outside the remit of services on offer from Macmillan and I examined how discussions involving one of these 'difficult topics' - the patient's prognosis - unfolded. While requests for a prognosis are specific to callers affected by cancer, future research could examine 'difficult' topics associated with other medical helplines to compare the kinds of interactional trouble that occurs and how it arises (e.g. whether it was due to the use of similar conversational practices). This comparative work was proposed at a workshop hosted by the Helplines Partnership in October 2015 and was received positively by key stakeholders within these organisations.

Finally, I would recommend that future research should closely collaborate with the helpline under examination and ensure that the organisation is kept up-to-date with key analytic findings and project progression. Such collaborations ensure that the research team is informed about changes within the helpline

and key figures such as managers and call-handlers can offer insights on the focus of analyses (i.e. if it is relevant to their everyday practice) as well as other avenues to pursue. Furthermore, close partnerships between the organisation and the academic team can facilitate the implementation of practical recommendations in the future (if applicable).

7.6 Concluding Remarks

Cancer is a widespread and feared disease that can have a devastating impact upon a patient's physical and emotional well-being as well as causing distress for families, friends and informal carers. Those affected by cancer have an array of informational and psychosocial needs and many are turning to a range of health services to fulfil them, including cancer helplines. This research showed that cancer patients and their significant others telephoned the Macmillan helpline for assistance about a considerable range of medical problems including information about current treatment, troubling symptoms, uncertain future matters as well as how best to support friends and relatives living with cancer. Callers often volunteered two or more problems for discussion, and call-handlers drew upon their knowledge as cancer specialist nurses to try and assist callers with the help they needed - although they could not always fulfil the callers' expectations. This conversation-analytic examination of cancer helpline talk revealed how telephone-based cancer support was requested and delivered, as well as how the participants handled various challenges associated with talking about cancer on a helpline. This thesis was the first step in opening the 'black box' of cancer helpline communication but more qualitative research is certainly warranted to further understand the inner-workings of these health services.

Appendices

Appendix A - Breakdown of caller demographics based on each individual caller

	Code	Caller	M /F	Ethnicity	Cancer type	Cancer stage
1	PAT1	Patient	M	Not asked	Prostate	In treatment
2	PAT2	Patient	F	White British	Breast	In treatment
3	PAT3	Patient	M	White British	Prostate	In treatment
4	PAT4	Patient	F		Bowel	In treatment
5	PAT5	Patient	F		Terminal Lung	Not treatable
6	PAT6	Patient	M		Lung	In treatment
7	PAT7	Patient	F		Chronic Myeloid Leukaemia	<i>Not provided</i>
8	PAT8	Patient	F	<i>Not asked</i>	Ovarian	In treatment
9	PAT9	Patient	F	White	Breast	In treatment
10	PAT10	Patient	F		Breast	In treatment
11	PAT11	Patient	F	White British	Breast	In treatment
12	PAT12	Patient	F	White British	Bile duct	In treatment
13	PAT13	Patient	F	White British	Breast	Post-treatment
14	PAT14	Patient	F	White British	Ovarian recurrence	In treatment
15	PAT15	Patient	F	<i>Not asked</i>	Breast	In treatment
16	PAT16	Patient	F	White mixed	Womb	In treatment
17	PAT17	Patient	F	<i>Not asked</i>	Secondary Liver	Diagnosis-only
18	PAT18	Patient	F	White English	Non-Hodgkin Lymphoma	In treatment
19	PAT19	Patient	M	White British	Non-Hodgkin Lymphoma	Post-treatment
20	PAT20	Patient	F	<i>Not asked</i>	Breast	In treatment
21	PAT21	Patient	F	White, European	Hodgkin Lymphoma	In treatment
22	PAT22	Patient	M	Asian British	Chronic Lymphatic Leukaemia	In treatment
23	PAT23	Patient	F	White Caucasian	Breast	In treatment
24	PAT24	Patient	F	White British	Breast	In treatment
25	PAT25	Patient	F	White	Skin	In treatment
26	PAT26	Patient	F	White British	Breast	In treatment
27	PAT27	Patient	M	White	Stomach	In treatment
28	PAT28	Patient	M	White British	Stomach	In treatment
29	PAT29	Patient	F	White British	Breast	In treatment
30	PAT30	Patient	M	White	Testicular	In treatment
31	PAT31	Patient	F	White British	Oral	Diagnosis-only
32	PAT32	Patient	M	White	Prostate	In treatment
33	PAT33	Patient	M	White British	Breast	In treatment
34	PAT34	Patient	F	White British	Non-Hodgkin	In treatment

Appendix A

	Code	Caller	M /F	Ethnicity	Cancer type	Cancer stage
					Lymphoma	
35	PAT35	Patient	M	White British	Bowel	In treatment
36	PAT36	Patient	F	White	Secondary Lung	In treatment
37	PAT37	Patient	F	White British	Endometrial	In treatment
38	PAT38	Patient	F	White British	Myeloma	In treatment
39	PAT39	Patient	F	White British	Breast	Post-treatment
40	PAT40	Patient	M	White British	Prostate	In treatment
41	PAT41	Patient	F	Scottish British	Cervical	In treatment
42	PAT42	Patient	M	White English	Non-Hodgkin Lymphoma	In treatment
43	PAT43	Patient	F	White	Undiagnosed (but pos breast cancer in both breasts)	Pre-diagnosis
44	PAT44	Patient	F	White	Breast	In treatment
45	PAT45	Patient	F	White Irish	Secondary lung and liver (had breast cancer 14 years ago)	In treatment
46	PAT46	Patient	F	White	Incurable liver cancer	Not treatable
47	PAT47	Patient	F	White British	Bladder	In treatment
48	PAT48	Patient	F	White British	Thyroid	Diagnosis-only
49	PAT49	Patient	F	White British	Secondary anal cancer (had vulva in past)	In treatment
50	PAT50	Patient	M	White British	Throat and lymph gland	In treatment
51	PAT51	Patient	F	<i>Not asked</i>	Breast	In treatment
52	PAT52	Patient	F	Mixed (Welsh and English)	Shin bone (secondary, had kidney in past)	Diagnosis-only
53	PAT53	Patient	F	White English	Chronic Lymphatic Leukaemia	Diagnosis-only
54	REL1	Partner	M		Lung	In treatment
55	REL2	Relative	F	White	Lung	In treatment
56	REL3	Relative	F	White	Breast and bone (secondary)	In treatment
57	REL4	Relative	F	White, British	Lung	In treatment
58	REL5	Relative	F	White, British	Lung (secondary, had oesophageal in past)	In treatment
59	REL6	Partner	M	Not asked	Renal	In treatment
60	REL7	Relative	M	White British	Merkel cell	Post-treatment
61	REL8	Relative	F	Not asked	Prostate	In treatment
62	REL9	Relative	F	White, UK	Unknown primary (secondary's in Stomach and glands)	In treatment
63	REL10	Partner	F	White	Oesophageal	In treatment
64	REL11	Partner	F	White British	Prostate and Bone	In treatment

	Code	Caller	M /F	Ethnicity	Cancer type	Cancer stage
					(advanced	
65	REL12	Relative	F	Dual heritage	Prostate and bone cancer.	In treatment
66	REL13	Partner	F	Not asked	Skin cancer	In treatment
67	REL14	Relative	F		Mesothelioma	In treatment
68	REL15	Relative	F	White	Breast cancer	In treatment
69	REL16	Partner	F	White	Terminal lung	In treatment
70	REL17	Partner	M		Breast (in the past)	Post-treatment
71	REL18	Relative	F	White, British	Breast	In treatment
72	REL19	Relative	F	English	Bowel (advanced, gone into patient's liver)	In treatment
73	REL20	Relative	F	White, British	LPHD (a form of Hodgkin's disease)	Diagnosis-only
74	REL21	Relative	F	White, British	Bile duct	In treatment
75	REL22	Relative	F	White, British	Amyloid (a form of kidney cancer)	End of life
76	REL23	Partner	F	White	Prostate cancer (secondary, advanced)	In treatment
77	REL24	Relative	F	White	Inoperable liver	In treatment
78	REL25	Relative	F	White	Brain tumour (secondary, malignant melanoma is the primary)	In treatment
79	REL26	Relative	F	White, British	Lung	In treatment
80	REL27	Relative	F	White, British	Testicular	Diagnosis-only
81	REL28	Relative	F	White, British	Stage four lung	In treatment
82	REL29	Partner	F	White, British	Unknown primary	Diagnosis-only
83	REL30	Friend	F	White, British	Breast (and it has gone to the lymph nodes)	In treatment
84	REL31	Relative	F	Not asked	Breast	In treatment
85	REL32	Partner then pat	F/M	White	Bowel (lungs and spine too)	In treatment
86	REL33	Friend	F	White British	Secondary (unknown), had bowel cancer 7 years ago	In treatment
87	REL34	Partner	M	Not asked	Malignant melanoma	Diagnosis-only
88	REL35	Partner	M	Not asked	Possibly lung cancer	Pre-diagnosis
89	REL36	Partner	F	White	Oesophageal	In treatment
90	REL37	Partner	F	English	Prostate	Diagnosis-only
91	REL38	Relative	F	British	Breast	In treatment

Appendix A

	Code	Caller	M /F	Ethnicity	Cancer type	Cancer stage
92	REL39	Friend	F	White	Stomach	End of life
93	REL40	Partner	M	White Irish	Breast	Diagnosis-only
94	REL41	Relative	F	White	Ovarian	In treatment
95	REL42	Partner	F	English	Prostate and bowel	Not treatable
96	REL43	Relative	F	White	Unknown primary	End of life
97	REL44	Relative	F	White, British	Inoperable lung	Not treatable
98	REL45	Relative	F	White, British	Oesophageal	In treatment
99	REL46	Relative	F	<i>Not asked</i>	Stage four bowel	In treatment

Table Key

- 1) PAT/REL(number) – the code ascribed to each call to. This was used to navigate through the corpus and to anonymise the call.
- 2) Caller – the type of caller who phoned.
 - a. Patient;
 - b. Partner (including husband/wife, and life partners);
 - c. Relative (including siblings, offspring and in-laws); and
 - d. Friends.
- 3) M/F – the gender of the caller as male or female
- 4) Ethnicity – the caller’s ethnic origin as described in the caller’s own words.
- 5) Cancer type – the name of the patient’s cancer as described in the caller’s own words.
- 6) CA stage – the patient’s stage of diagnosis.
 - a. Pre-diagnosis;
 - b. Diagnosis;
 - c. In treatment;
 - d. Post-treatment;
 - e. Not treatable; and
 - f. End of life

Cells that are coloured grey represent ‘nurse only’ calls (i.e. we do not have access to the ISO call where this demographic data was collected).

Appendix B – Breakdown of key call information

	Caller Code	ISO call length	Nurse call length	ISO code	Nurse code
1	PAT 1	03:32	14:15	ISO 7	Nurse 6
2	PAT 2	03:56	06:35	ISO 17	Nurse 5
3	PAT 3	08:10	32:18	ISO 3	Nurse 8
4	PAT 4		16:42		Nurse 8
5	PAT 5		10:04		Nurse 9
6	PAT 6		10:36		Nurse 8
7	PAT 7		01:18		Nurse 11
8	PAT 8	03:05	05:10	ISO 21	Nurse 13
9	PAT 9	06:45	05:03	ISO 1	Nurse 3
10	PAT 10	05:34	19:01	ISO 13	Nurse 16
11	PAT 11	36:05	14:02	ISO 3	Nurse 3
12	PAT 12	03:46	22:48	ISO 6	Nurse 16
13	PAT 13	07:38	09:43	ISO 3	Nurse 8
14	PAT 14	03:02	03:19	ISO 11	Nurse 2
15	PAT 15	03:26	11:03	ISO 6	Nurse 2
16	PAT 16	04:20	27:55	ISO 13	Nurse 6
17	PAT 17	04:52	49:17	ISO 8	Nurse 7
18	PAT 18	05:38	05:28	ISO 1	Nurse 9
19	PAT 19	03:59	18:48	ISO 16	Nurse 8
20	PAT 20	02:31	13:03	ISO 16	Nurse 4
21	PAT 21	03:04	17:25	ISO 3	Nurse 10
22	PAT 22	07:41	10:15	ISO 13	Nurse 6
23	PAT 23	11:14	34:23	ISO 3	Nurse 2
24	PAT 24	03:02	18:08	ISO 3	Nurse 3
25	PAT 25	17:59	05:13	ISO 17	Nurse 15
26	PAT 26	13:37	26:46	ISO 13	Nurse 8
27	PAT 27	12:42	08:37	ISO 14	Nurse 13
28	PAT 28	07:32	28:00	ISO 1	Nurse 16
29	PAT 29	03:48	18:03	ISO 3	Nurse 6
30	PAT 30	03:07	56:53	ISO 16	Nurse 4
31	PAT 31	03:38	09:06	ISO 10	Nurse 9
32	PAT 32	04:29	03:04	ISO 14	Nurse 10
33	PAT 33	03:43	09:16	ISO 13	Nurse 15
34	PAT 34	03:02	16:52	ISO 7	Nurse 14
35	PAT 35	03:09	03:12	ISO 3	Nurse 6
36	PAT 36	04:04	34:54	ISO 12	Nurse 8
37	PAT 37	04:46	10:02	ISO 3	Nurse 10
38	PAT 38	04:03	11:11	ISO 5	Nurse 1
39	PAT 39	03:13	15:40	ISO 17	Nurse 8
40	PAT 40	03:48	12:11	ISO 16	Nurse 4

Appendix B

	Caller Code	ISO call length	Nurse call length	ISO code	Nurse code
41	PAT 41	04:23	08:59	ISO 17	Nurse 5
42	PAT 42	01:48	02:20	ISO 7	Nurse 1
43	PAT 43	10:44	08:59	ISO 1	Nurse 1
44	PAT 44	06:30	02:44	ISO 4	Nurse 1
45	PAT 45	11:39	22:33	ISO 9	Nurse 5
46	PAT 46	34:00	34:00	ISO 1	Nurse 16
47	PAT 47	03:53	32:48	ISO 16	Nurse 10
48	PAT 48	02:18	18:30	ISO 16	Nurse 4
49	PAT 49	05:56	12:05	ISO 19	Nurse 7
50	PAT 50	10:41	20:25	ISO 10	Nurse 4
51	PAT 51	02:46	02:54	ISO 16	Nurse 15
52	PAT 52	08:26	24:50	ISO 17	Nurse 9
53	PAT53	03:27	05:46	ISO 18	Nurse 15
54	Rel 1		17:58	ISO 17	Nurse 1
55	Rel 2	02:46	08:04	ISO 17	Nurse 12
56	Rel 3	07:18	23:05	ISO 17	Nurse 12
57	Rel 4	13:02	16:25	ISO 1	Nurse 8
58	Rel 5	04:29	03:18	ISO 3	Nurse 9
59	Rel 6	14:49	03:01	ISO 13	Nurse 10
60	Rel 7		20:07	ISO 3	Nurse 8
61	Rel 8	03:51	04:16	ISO 7	Nurse 15
62	Rel 9	04:03	04:05	ISO 8	Nurse 1
63	Rel 10	02:37	12:43	ISO 8	Nurse 4
64	Rel 11	08:34	28:49	ISO 7	Nurse 3
65	Rel 12	05:15	22:06	ISO 17	Nurse 10
66	Rel 13	07:52	03:15	ISO 13	Nurse 6
67	Rel 14		31:01		Nurse 11
68	Rel 15	03:12	25:45	ISO 7	Nurse 1
69	Rel 16	27:48	22:48	ISO 13	Nurse 16
70	Rel 17		26:12		ISO 20
71	Rel 18	07:36	20:12	ISO 1	Nurse 8
72	Rel 19	10:45	08:05	ISO 3	Nurse 5
73	Rel 20	4:00	11:57	ISO 12	Nurse 11
74	Rel 21	09:08	16:01	ISO 1	Nurse 4
75	Rel 22	3:52	09:23	ISO 3	Nurse 9
76	Rel 23	03:54	10:53	ISO 13	Nurse 8
77	Rel 24	09:19	18:28	ISO 17	Nurse 7
78	Rel 25	03:29	19:38	ISO 10	Nurse 8
79	Rel 26	05:22	10:46	ISO 2	Nurse 9
80	Rel 27	07:26	20:15	ISO 17	Nurse 7
81	Rel 28	09:09	09:03	ISO 17	Nurse 1
82	Rel 29	09:27	09:13	ISO 14	Nurse 7
83	Rel 30	04:02	14:56	ISO 7	Nurse 6
84	Rel 31	28:00	20:46	ISO 13	Nurse 6

	Caller Code	ISO call length	Nurse call length	ISO code	Nurse code
85	Rel 32	10:01	15:10	ISO 12	Nurse 13
86	Rel 33	38:57	17:12	ISO 7	Nurse 1
87	Rel 34	03:31	13:22	ISO 3	Nurse 8
88	Rel 35	04:09	09:19	ISO 17	Nurse 17
89	Rel 36	06:38	20:11	ISO 17	Nurse 17
90	Rel 37	04:35	48:00	ISO 17	Nurse 1
91	Rel 38	10:19	5:18	ISO 17	Nurse 10
92	Rel 39	08:40	46:01	ISO 17	Nurse 18
93	Rel 40	04:46	12:44	ISO 12	Nurse 10
94	Rel 41	11:45	12:10	ISO 17	Nurse 4
95	Rel 42	07:21	34:48	ISO 13	Nurse 7
96	Rel 43	20:44	29:00	ISO 12	Nurse 18
97	Rel 44	16:36	17:06	ISO 12	Nurse 2
98	Rel 45	05:13	09:28	ISO 19	Nurse 2
99	Rel 46	03:54	41:15	ISO 16	Nurse 8

Appendix C - CA Transcription Symbols

These are the main transcription symbols used for CA analyses (adapted from Jefferson, 2004 and Hepburn and Bolden, 2014).

(.)	Micro-pause – less than a tenth of a second
(0.2), (2.6)	Examples of timed pauses (in seconds)
↑word	Onset of noticeable pitch rise
↓word	Onset of noticeable pitch fall
A: wor[d B: [word	Square brackets aligned across adjacent lines denote the start of overlapping speech
.	Falling vocal pitch
?	Rising vocal pitch
.hhh	In-breath
hhh	Out-breath
wo(h)rd	Within-speech aspirations
wor-	A sharp cut-off
wo:rd	Colons show that the speaker has stretched the preceding sound
(words)	A guess at what might have been said if unclear
A: word= B: =word	The equals sign shows that there is no discernible pause between two speakers' turns
<u>word</u>	Vocal emphasis
WORD	Talk pronounced loudly in comparison with surrounding talk
° word °	Talk between “degree signs” is quieter than surrounding talk
>word word<	Talk between inward arrows is delivered faster than surrounding talk
<word word>	Talk between outward arrows is delivered slower than surrounding talk
((sniff))	Transcriber's effort at representing something difficult, or impossible, to write phonetically

Appendix D – Invitation for callers to take part in the helpline study



Date

Dear

Invitation to take part in the Research Study entitled:

SPEAK:

A conversation analysis of Specialist cancer helpline work

During your recent call to the Macmillan Cancer Support helpline, you expressed an interest to be contacted about research occurring at the helpline. We are conducting research about helpline communication, in particular how helpline callers and call takers communicate and what can contribute to effective communication on helplines. We are inviting you to participate in this study by allowing us to analyse the anonymised audio recording of the call you recently had with a Macmillan Cancer Support helpline call taker (no names/places will be identifiable). We may also invite you, in the future, to take part in one informal interview with a researcher about your helpline use.

It is important for you to know that:

1. Taking part in the research will not affect your future use of helpline services.
2. It is entirely up to you if you wish to take part.
3. If you do not reply we will contact you once more to remind you.
4. If we do not hear from you following our reminder we will not contact you again about this study.
5. Speaking with the researcher will not in any way constitute consent, you would still free to decline to take part and we will not contact you again.

What to do next:

Enclosed with this letter you will find an information leaflet which we would like you to read before you decide whether to get in touch with us or take part. The information leaflet describes the study in greater detail. It also includes our telephone number if you have any questions about the study. We have included a consent form if you are happy for us to use your anonymised MCS helpline. We have also enclosed a reply slip (direct to us) on which you can state whether you are happy for us to contact you later about the interview study. You do not have to agree to both parts of the research. Your consent form and/or reply slip can be sent to us in the freepost envelope provided. Many thanks for your time.

Yours sincerely

Dr Geraldine Leydon
Chief Investigator
Enc.

Katie Simmons
Research Fellow

Reply slip:

Once you have thought about the information, please reply to us using the reply slip.

1. Please fill in the reply slip below.

Appendix D

2. Please place it in the addressed freepost envelope (does not require a stamp).
3. Seal and post the envelope.
4. The envelope will be opened only by a member of the research team, who will call you or e-mail you to explain the interview study, and discuss your participation in an interview (lasting approx. 1 hour).

REPLY SLIP

Please tick

<p>I WOULD be happy to be contacted in the future about participation in an informal telephone interview with a researcher.</p> <p>If you would like to hear more please complete below fully:</p> <p>Date of birth: _____ / _____ / _____ Email address: _____</p> <p>Address: _____ Contact telephone numbers: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Post code _____</p>		✓
<p>OR I WOULD NOT like to be contacted about an interview</p>		
Name:		
Date:		

Many thanks for taking the time to read this information and completing our reply slip.

Appendix E – Participant information sheet (for callers)

SPEAK: A Study of **S**PECIALIST **c**ANCER helpline work**K**

Information sheet for participants (Caller)

We would like to invite you to take part in this study. If you decide that you wish to take part it will involve you allowing us to use the audio recording of your call with a call taker at the Macmillan Cancer Support helpline.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. You are also welcome to contact the research team to discuss the study on the number provided overleaf.

Part 1 tells you the purpose of the study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Please ask us if there is anything which is not clear or you would like more information.

Please take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

The purpose of this study is to find out how helpline callers and call takers communicate and what can contribute to effective communication on helplines.

Why have I been chosen?

You are being invited to take part because you have been a caller to the Macmillan Cancer Support helpline.

Do I have to take part?

Participation in this research study is entirely voluntary. It is up to you to decide whether to take part. You are able to withdraw at any time without giving any reason and this would not affect the standard of any future care that you receive from Macmillan Cancer Support.

What will happen to me if I take part?

We will invite you to take part by asking you if you will allow us to use the audio recording of your call with a call taker on the Macmillan Cancer Support helpline. The audio recording will be typed up and analysed using a well used

Appendix E

method called Conversational Analysis. The research will look at communication between call takers and callers. Excerpts of the anonymised recorded helpline calls may be used for teaching, training, professional meetings and/or in data workshops with professional Conversation Analysts who are skilled at dealing with anonymised data of this kind (subject to your consent).

A small number of callers who agree to have their recording used, may also be asked to take part in a future follow up interview, which would take place at a place of convenience (e.g. your home) or you may be interviewed over the phone. We would ask you questions about your experience of using the helpline and about how you felt about taking part in the study. The interview would be recorded and typed up at a later date. The interview would last around 30- 60 minutes. Any travel costs would be reimbursed.

What are the possible benefits and risks of taking part?

There are no specific benefits of taking part in this part of the study, however the findings may contribute to a better understanding of effective communication between call takers and callers on cancer helplines and may lead to a Training Information Package for caller takers. There are no risks to taking part in this study, however a disadvantage to taking part is that you may be invited to be interviewed and this will involve time committed for an interview.

Part 2

What if there was a problem?

If you have any concerns or complaints about any aspects of how this research has been conducted. You may write or ask to speak to the researchers who will do their best to answer your questions (contact details on page 2 of this information sheet). If you remain unhappy and wish to complain formally please contact, Dr Martina Prude, Research Governance Manager, University of Southampton, Room 4009, Legal Services, Building 37, Highfield, Southampton, SO17 1BJ. Telephone: 023 8059 8848/9 or email: mad4@soton.ac.uk

Will my taking part be kept confidential?

Audio encrypted digital files will be sent on a military USB key directly to the professional transcription company by Macmillan Cancer Support. The transcription company will anonymise the audio data on behalf of Macmillan Cancer Support. This anonymised data, in both typed transcription and anonymised audio files, will then be passed onto the research team at the UoS for analysis. Information produced by this study will be stored in the Researcher's locked file and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate secure location. It is normal for study data to be transferred to computer and it is important that this transfer is carried out accurately and your name and address is not transferred to computer with the data. In the storage of information there will be full adherence to the current Data Protection Act. Information contained in your records with your name on it may not be given to anyone not connected with the study without your written consent. Confidentiality will be assured, however in very exceptional cases participants might raise issues that indicate possible or actual serious harm to others and this may warrant breaking confidentiality. In the unlikely event that

this should happen the researcher would discuss this decision with the participant and notify an appropriate organisation or individual. All data will be stored in accordance with research governance for 15 years.

What will happen to the findings?

The findings from the audio recordings and the interviews will contribute to the development of a Training Information Package for call takers. The results may be published in recognised journals and also through international meetings. The voices on the audio data will not be distorted, however all audio and transcription data will be anonymised so that any reference to individual names and places will be removed and pseudonyms will be used instead. These anonymised clips of audio recordings and anonymised quotes from the transcribed recordings may also be used in conference presentations and for teaching purposes.

Who is organising the funding?

The study is funded by the Department of Health National Institute for Health Research (NIHR).

Who has reviewed the study?

The study has been reviewed by several experts in the field as part of the application for funding from the NIHR.

Contact for further information?

If you require further information, please contact a member of the research team:

Dr Geraldine Leydon (Chief Investigator)
 Primary Medical Care
 The University of Southampton
 Aldermoor Health Centre
 Aldermoor Close
 Southampton
 SO16 5ST
 Email: G.M.Leydon@soton.ac.uk
 Tel: 023 8024 1048

Katie Simmons (Research Fellow)
 Primary Medical Care
 The University of Southampton
 Aldermoor Health Centre
 Aldermoor Close
 Southampton
 SO16 5ST
 Email: K.Simmons@soton.ac.uk
 Tel: 023 8024 1063

Thank you for making the time to read this Information Sheet. This is a copy for you to keep for your reference.

Appendix F – Participant Consent form (for callers)

CONSENT FORM (Caller)

Title of the project:

SPEAK:

A conversation analysis of **SPE**cialist **cA**ncer helpline work**K**

Please initial box:

1. I confirm that I have read and understand the Information Sheet for the above study and had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my future use of helpline services being affected. The recorded audio files of my telephone call will be destroyed in the event of my withdrawal from the study.
3. I agree to take part in the study.
4. I agree that my call with the Macmillan Cancer Services helpline call taker can be used for this research.
5. I agree that an anonymous form of the written and sound material (where place and location names have been removed, but voices will not be distorted) collected in this study can be used for future studies using other methods of language and communication analysis.
6. I agree that an anonymous form of the written and sound material (where place and location names have been removed, but voices will not be distorted) can be used in conference presentations and publications about the findings of this study and to teach healthcare students and professionals.
7. I agree that an anonymous form of the sound material from the recorded calls can be used in research meetings and publications and to teach healthcare students and professionals
8. I agree that the researcher can in the future invite me to take part in an interview about my use of Specialist Cancer Helplines and I have provided my contact details on your Reply Slip so you can contact me about an interview.

Name:

Signature:

Appendix G – Participant information sheet (for call-handlers)



SPEAK:

A study of **SPE**cialist **cA**ncer helpline work**K**

Information sheet for participants (Call-taker)

We would like to invite you to take part in this study. If you decide that you wish to take part, it will involve you allowing us to use the audio recording of one or more of your calls with a caller(s) to the Macmillan Cancer Support helpline. A small number of call-takers will also be asked to take part in an informal interview with the Research Fellow.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of the study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Please ask us if there is anything which is not clear or you would like more information.

Please take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

The purpose of this study is to find out how helpline callers and call takers communicate and what can contribute to effective communication on helplines.

Why have I been chosen?

You are being invited to take part because you are an experienced Macmillan Cancer Support call taker.

Do I have to take part?

Participation in this research study is entirely voluntary. It is up to you to decide whether to take part. You are able to withdraw at any time without giving any reason.

What will happen to me if I take part?

We will invite you to take part by asking you if you will allow us to use recordings of your calls with callers to the Macmillan Cancer Support helpline. The audio recordings will be typed up and analysed using a well used method called Conversation Analysis. The research will look at communication between

Appendix G

call takers and callers (in a non-judgemental way). The recordings would be confidentially and professionally typed up, removing all identifiable data before passing the data to the research team at Southampton University. If you agree to us using audio-recording(s) of your call(s), you may also be asked to take part in an informal interview, at Macmillan's offices or you may prefer to be interviewed over the telephone. We would ask questions about the research study and how you felt taking part. We would also ask for your views on providing telephone help. The interview would be recorded and typed up at a later date. The interview would last for around 30-60 minutes. Interviews will be typed up and all identifiable material removed (names and places). Data extracts / quotations may be used for peer review publication and conference presentation. Exctracts of the anonymised recorded helpline calls may be used for teaching, training, professional meetings and/or in data workshops with professional Conversation Analysts who are skilled at dealing with anonymised data of this kind (subject to your consent).

What are the possible benefits and risks of taking part?

There are no specific benefits of taking part in this part of the study. However the findings may contribute to a better understanding of communication between call takers and callers on cancer helplines and may lead to a Training Information Package for helpline service providers. There are no risks to taking part in this study, however a possible disadvantage to taking part is time committed to an interview should you wish to take part.

Part 2

What if there was a problem?

If you have any concerns or complaints about any aspects of how this research has been conducted. You may write or ask to speak to the researchers who will do their best to answer your questions (contact details below). If you remain unhappy and wish to complain formally you can contact, Dr Martina Prude, Research Governance Manager, University of Southampton, Room 4009, Legal Services, Building 37, Highfield, Southampton, SO17 1BJ. Telephone: 023 8059 8848/9 or email: mad4@soton.ac.uk

Will my taking part be kept confidential?

Audio encrypted digital files will be sent on a military USB key directly to the professional transcription company by Macmillan Cancer Support. The transcription company will anonymise the audio data on behalf of Macmillan Cancer Support. This anonymised data, in both typed transcription and anonymised audio files, will then be passed onto the research team at the UoS for analysis. Information produced by this study will be stored in the Researcher's locked file and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate secure location. It is normal for study data to be transferred to computer and it is important that this transfer is carried out accurately and your name and address is not transferred to computer with the data. In the storage of information there will be full adherence to the current Data Protection Act. Confidentiality will be assured, however in very exceptional cases participants might raise issues that indicate possible or actual serious harm to others and this may warrant breaking confidentiality. In the unlikely event that this should happen the researcher would discuss this decision with MCS/the participant and notify an appropriate organisation or individual.

All data will be stored in accordance with research governance for 15 years.

What will happen to the findings?

The findings from the audio recordings and the interviews will contribute to the development of a Training Information Package for call takers/helpline services. The results may be published in recognised journals and also through international meetings. The voices on the audio data will not be distorted, however all audio and transcription data will be anonymised so that any reference to individual names and places will be removed and pseudonyms will be used instead. These anonymised clips of audio recordings and anonymised quotes from the transcribed recordings may also be used in conference presentations and for teaching purposes.

Who is organising the funding?

The study is funded by the Department of Health National Institute for Health Research (NIHR) and Dimbleby Cancer Care.

Who has reviewed the study?

The study has been reviewed by several experts in the field as part of the application for funding from the NIHR. Ethical Approval has also been obtained from UoS Faculty of Medicine Ethics Committee.

Contact for further information?

If you require further information, please contact a member of the research team:

Dr Geraldine Leydon (Chief Investigator)
Primary Medical Care
The University of Southampton
Aldermoor Health Centre
Aldermoor Close
Southampton
SO16 5ST
Email: G.M.Leydon@soton.ac.uk
Tel: 023 8024 1048

Katie Simmons (Research Fellow)
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Tel: 023 8024 1063

Thank you for making the time to read this Information Sheet. This is a copy for you to keep for your reference.

Appendix H – Participant consent form (for call-handlers)



SPEAK:

A study of SPEcialist cANcer helpline work

CONSENT FORM (Call Taker)

Please initial box:

I confirm that I have read and understand the Information Sheet (dated 3rd February 2011, Version 3) for the above study and had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. The recorded audio files of my telephone call will be destroyed in the event of my withdrawal from the study.

I agree to take part in the study.

I agree that a sample of my calls with callers can be used for this research.

I agree that an anonymous form of the written and sound material (where place and location names have been removed, but voices will not be distorted) collected in this study can be used for future studies using other methods of language and communication analysis.

I agree that an anonymous form of the written and sound material (where place and location names have been removed, but voices will not be distorted) can be used in conference presentations and publications about the findings of this study and to teach healthcare students and professionals.

I agree that the researcher can in the future invite me to take part in an interview about my work for Specialist Cancer Helplines

Name (please print): _____

Signature: _____

Note: Please keep a copy for yourself and return the original copy to us in the freepost reply envelope provided

Appendix I - A detailed breakdown of the helpline's phase structure

<p>1. ISO opening</p> <p>ISO opening solicitation. This is usually <i>You're through to Macmillan Cancer Support, how may I help you</i> or <i>You're through to Macmillan Cancer Support, my name is ((NAME)) how may I help you.</i></p>
<p>2. Caller problem presentation</p>
<p>3. Data gathering</p> <p>The ISO informs the caller that they need to be triaged to a cancer specialist nurse and asks a series of questions to create a new call record.</p> <ul style="list-style-type: none"> i) The ISO handles the caller's RFC because the medically-related nature of the concern is not immediately apparent. The ISO may offer information/advice/ emotional support before triaging the caller at a later point during the call. This is more likely to happen with relative callers and callers who are distressed.
<p>4. ISO Pre-closing</p> <p>The ISO checks if a nurse is available.</p> <ul style="list-style-type: none"> i) The ISO informs the caller they are about to be put on hold as they are triaged to a nurse. ii) A nurse is unavailable and the ISO informs the caller they will arrange a nurse call-back. The ISO may solicit further concerns, <i>anything else I can help with in the meantime</i>, before closing the call.
<p>5. ISO Call closing</p> <p>The caller aligns to the closing with the appreciation <i>thank you</i> and terminal utterances are exchanged to end the interaction.</p>
<p>6. Triage/Nurse call-back</p> <ul style="list-style-type: none"> i) The ISO provides the nurse with a brief summary about the caller's reason for calling and a reference number so the nurse can access and update the caller's record throughout the call. This record notes the information/advice provided and is stored on a Macmillan database in case the caller phones again in the future.

- ii) A nurse call back is arranged and takes place within 48 hours of the first call taking place.

7. Nurse call opening

- i) The nurse displays no knowledge of the caller's problem and opens the interaction with "how can I help". The caller produces a similar problem presentation first described to the ISO.
- ii) The nurse displays knowledge of the caller's problem and opens the interaction with a short summary about their concern. The caller then confirms and expands on the details provided by the nurse.

8. Caller problem presentation

The caller presents a medically-related problem to a nurse.

9. Nurse data gathering

The nurse asks the caller a series of medically-related questions about caller's reason for calling. This sequence varies in length between each call.

- i) The nurse prefaces their response with a turn which highlights that they may not be able to provide the caller with the requested information. This is a device used to manage caller expectations of what the helpline is able to provide.
- ii) The nurse immediately responds to the caller's request with information/ advice/ emotional support. Nurses are more likely to do this if the caller's concern is straightforward (i.e. information-giving) or if the caller is distressed.

10. Nurse response

The nurse responds to the caller's request with one or more of several key outcomes:

1. Information (verbal information; a booklet offer or a useful website);
2. Advice (advice to talk with another healthcare professional; medical advice; or a telephone number);
3. Psychosocial support (reassurance; the name of a support group);
4. Or the caller is put on hold.

Nurses overwhelmingly provide verbal information first and produce one of the outcomes listed above toward the end of the sequence. These sequences can extend several turns, with the nurse providing information/advice and callers

asking follow-up questions. If the follow-up questions remain topically coherent with the current sequence they are considered as part of the current activity rather than a separate one, as recommended by Heritage and Sorjonen (1994).

11. Sequence closing

- i) The caller receipts the information/advice by showing they have understood the information provided (e.g. with an appreciation, *thanks for that*, a K+ marker, *oh I didn't realise until you just said*, etc), or that they will follow-up on the nurse's recommendation (e.g. *I'll phone up tomorrow*). The caller may then close the call or raise another concern.
- ii) The nurse may repeat part of their advice or provide a summary to show the sequence is now closed.

12. Caller additional concern

The caller requests information/advice about another problem. This may come in the form of another problem presentation or it may be designed as a question:

- i) The concern is initiated by the caller;
- ii) The caller's problem is touched off from something the nurse said;
- iii) The nurse raises a concern based something the caller said.

Phases 7-9 are repeated.

13. Call closing

Moves into closing

- i) The caller produces a closing move with an appreciation *thank you for your help*. This may be designed in the routine way (as with the latter design), or upgraded/downgraded to display different levels of caller satisfaction.
- ii) The nurse offers to send the caller information or finalises an arrangement made previously in the call which moves participants toward a closing section. The nurse may produce an elongated *oka:::y* to ensure the caller is ready to close (if they displayed an unwillingness) thus displaying an orientation to callers making a more definitive closing move. Callers frequently provide an appreciation at some point during this sequence which brings the call toward closure.

Activities within closing

- i) The nurse provides two closing implicative turns, one that asks the caller for their consent to keep a record of the call, and one that encourages the caller to use the helpline again in the future.
- ii) Reciprocal terminal exchanges are produced to terminate the call.

Activities that may occur within closing

- I. The nurse offers to send the caller information after the caller has made a closing move.
- II. The caller initiates an additional concern in closing. Nurses usually repeat.
- III. advice/ information previously provided earlier on in the call thus suggesting they do not consider concerns raised here as another matter that needs to be unpacked and discussed in full.
- IV. The nurse repeats advice previous provided in the main body of the call.

Appendix J - Example of a full matched nurse call with the phases, problems and responses highlighted

Call Details

Call Name: Pat 39
ISO: ISO 17
Nurse: Nurse 8
Call type: Nurse call-back
Call length: 3:48m (ISO call) and 18:03m (nurse call)
Caller: Female cancer patient
Cancer type: Breast
Stage of diagnosis: In treatment (had a lumpectomy and reconstructive surgery 10 days ago)

ISO OPENING

 1 ISO: .hhh Good afternoon you're through to macmillan support
 2 li:ne, how can I help.

CALLER PROBLEM PRESENTATION - TREATMENT INFORMATION

 3 C: Hello um, (.) I've just ten da:ys ago: had u::m, (.) a a:
 4 lum::pectomy: and reconstructive surgery.
 5 (.)
 6 ISO: Aha,
 7 C: And um (.) >I've been given some information yesterday<
 8 (.) .hh from the doctor about the fact that I'm
 9 apparently borde:rline (.) .hhh u::m (.) because of the
 10 si::ze u::m (.) of the lu:mp o:n either (.) u:m having
 11 chemotherapy or not having chemotherapy.=
 12 ISO: =Aha,
 13 C: And I'm trying to find out statistics to sort of give me
 14 a little bit of u::m (.) help as to how to make that
 15 decision.

Appendix J

ISO DATA GATHERING

16 ISO: Okay.=I::: won't be able to tell you but what I will do
17 have you phoned up before?

18 C: No:.

19 ISO: Okay let me:: do you want to give your details or no.

20 C: I'm quite happy to give y[ou my details]

21 ISO: [Okay let me take] some: details
22 off you:: and then I:'ll see if I have a nurse avai:lable
23 I'll put your through to a nurse.

24 C: Thank you:.

25 ISO: Okay ju:st bear with me one second (.) .HHHHH HHHHH
26 (3.8)

27 ISO: Can I have you:r postco:de plea::se,
28 C: X X X
29 ISO: X X?
30 C: X (.) for moth[er
31 ISO: [O:kay I'll alri:ght okay just bear with me
32 one min- something has happened to the (0.6) my
33 compu:te:::r
34 (3.6)

35 ISO: X:: X: X,
36 C: X,
37 ISO: Aha::,
38 C: X X.
39 ISO: X X: (.) and house number,
40 C: X,
41 ISO: X X::.. That's ((repeats address))?
42 C: Tha::t's i::t
43 ISO: ((location name)).
44 (0.4)

45 ISO: A:::nd (.) your first name is it miss or Mrs?
46 C: Mrs ((surname)).
47 ISO: ((na:::me)),
48 C: Yea.
49 ISO: ((name)) your last na:::me,
50 C: †((surname)).
51 ISO: ((surname)) ((typing)) (0.6) Do you want me: (.) to
52 call you >((first name)) or ((Mrs surname)).<
53 C: ((first name)) will be fi[ne.
54 ISO: [O:::h okay (.) thank you

55 ((name)). .hhh Can I have your date of birth plea:[se
56 C: [X X
57 (0.6) X[X
58 ISO: [((repeats date of birth)) .hh ↑A::nd you're
59 whi:te Briti:sh?
60 C: Yea.
61 ISO: And can I have your home phone numbe::r,
62 C: Er X X X X X
63 ISO: Mm hm,
64 C: X X X X X
65 ISO: X X. And ((name)) last few questions these are optional
66 please feel free to say no::: .hh can we keep you
67 info:rmed about the work we are doing for people living
68 with cancer?
69 C: ↑Yea.
70 ISO: E::r would you l- li::ke to take pa::rt in stu- studies
71 or resea:rch that Macmillan doe:s from time to ti:me?
72 C: Possibly::
73 ISO: Alri:ght that would be in the form of su:rvey giving
74 feedback on our services you'll be[::: (.)] conta:cted
75 C: [°okay.°]
76 ISO: once a yea:r by Macmillan or by our trusted researchers
77 like a hospital or a university.
78 C: Okay.

ISO CALL CLOSING

- - - - -
79 ISO: .hh Oka::y. ((name)) le:t me see if I ha::ve >someone
80 available< if no:t I'll come back to you::
81 C: Alri:ght then
82 (0.6)
83 ISO: Ju:::st give me a second to check
84 (3.8)
85 ISO: A::h no::: unfortunately I do::n't have anyo:ne (.)
86 ↑What I can do:((name))I ca::n ask them to call you ba::ck
87 which would be in the next few hou::rs will that be
88 alright o[r] will you call back.
89 C: [Ye]
90 C: ↑U::m (.) I don't mi:nd we can try either way.
91 ISO: Okay (.) you can try:: as we::ll we have your details and
92 if you::: are put through to a nurse just tell them there

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93 is a call back to cancel it.
94 (.)
95 C: Okay then.
96 ISO: I'll do that as well so that it's (.) both ways it's
97 covered
98 C: Okay then .
99 ISO: Oka::y and you also try after sometime >because this is
100 lunch hour< maybe:: (.) some have gone on lu:nch and er
101 five six are taking ↑ca::lls,
102 C: Ye.
103 ISO: So I::: would suggest give us a call after maybe one
104 hour agai::n
105 C: Alri[ght then.
106 ISO: [And just give your postcode because we have your
107 details now.
108 C: Okay then I'll d[o that]
109 ISO: [A:::nd] er this is the best number to
110 call you ba::ck?
111 C: Yes it i[s]
112 ISO: [O:]::kay Al:- I'll do tha::t and I'm sorry no
113 one is available
114 C: £Th(h)at's ok(h)a:::y£
115 ISO: Anything else I can help you with
116 C: Not for now thank you very much:
117 ISO: Okay if at ↑a::ll there is anything if you are having a
118 bad day if you want to have a cha:::t just just a chit
119 cha:t plea:::se jus- just give us a call ba:ck.
120 C: Thank you very mu::ch
121 ISO: Okay you take care
122 C: Bye the:n
123 ISO: Buby.

NURSE OPENING - CALL-BACK

(telephone ringing)
124 C: X X X X X X?
125 N: Hello is that ((name))?
126 C: Yes it i:s
127 N: Hi: the:re, this is ((name)) calling from Macmillan
128 Cancer Suppo:rt?

129 C: Oh hello::
 130 N: Hi I'm one of the nu::rses, I've been given a message to
 131 >give you a little< (.) call ba::ck?
 132 C: Oh that's very ki:nd of you, thank you.
 133 N: ↓Hi:::

CALLER PROBLEM PRESENTATION - TREATMENT INFORMATION

 134 C: U::m, (.) well the reason why I was ringing was because I
 135 wondered if there were (.) so:me figures or sta- (.)
 136 statistics that would help me u:m make a decision as to
 137 whether to .hh have chemo or no:t be[cause,] (.) um,=
 138 N: [↑O::°kay°]
 139 C: I'm on the borderli:ne um I'm statis- ↓Well (.) the, (.)
 140 surgeon said yesterday (.) .hh I've got a:: I had this
 141 two:: centimetre lump,
 142 N: Mm hm,
 143 C: And he's said that tha::t's (.) indicated that tha:t (.)
 144 that was the line where (.) you know (.) sort of I could
 145 make eith- I could go either wa::y.
 146 N: Mm hm,
 147 C: And u::m (.) and now my sister had breast cancer about
 148 >seven years ago< and she had a similar decision to make
 149 a::nd er she decided not to have chemo and everything
 150 seemed to be working out with her .hh So I'm sort of um,
 151 (.) [I'm tryi]ng to weigh up wh[at's]the damage.
 152 N: [°Mm: hm°] [MM::.]

NURSE DATA GATHERING

 153 N: ↑Oka:y. So you had a a two centimetre lump,
 154 C: Yes.
 155 N: And you've had that remo:ved,
 156 C: ↑Ye:s.
 157 N: And have you had- are you having any radiotherapy?
 158 C: E::r I will do yeah I had the operation u::m (.) two
 159 weeks this Thur[sday]
 160 N: [O:::kay so] it's not that long ago .hhh
 161 a::nd (.) did you have any lymph no:des? (0.4) t[aken]
 162 C: [Yeah]

Appendix J

163 the lymph nodes were fine.

NURSE RESPONSE - VERBAL INFORMATION

164 N: They were fine. Okay .HHHHHHHHH (.) ↑Well, (0.4) #er#
165 you may have understood this already but (0.4) the reason
166 why: <doctors> (.) e- give patients (.) >the the< sort of
167 choice in a situation like this: is because #e#
168 (.) >sort of< ↑research and evidence in a
169 situation like this won't have shown any clear benefit
170 of (.) of (.) of having it or not having it.

171 C: Mm,

172 N: .hh Because (.) if there was a very very clear benefit,
173 (.) they would say (.) we want you to have it.

174 C: Yes,

175 N: They wouldn't (.) >sort of< (.) I mean (.) you know
176 (.) >nobody can force you to do anything you don't want
177 to do: but .hh

178 C: No.

179 N: They would recommend that you have it rather than
180 say in the choice is yours.

181 C: Yes

182 N: .hhhhh #I# I think statistics are fine and I can I'm happy
183 to have a look at them for you if I can find them #i- i-#
184 w- the i- it's a bit more tricky than just saying (.)
185 what happens in this situation because what I would=
186 C: [Mm,]
187 N: =.hh have to do is find a study that had women with
188 exactly that >size of a< lump and no lymph nodes=
189 C: [I see]
190 N: affected and in in your age group and (.) and all
191 those >sorts of things< and that becomes quite tricky
192 but I I can certainly have a look and see what I can
193 find. .hh but what what they'll tell you is what
194 the average was.

195 C: Okay. .hh You see he did (.)] He did give me one=
196 N: [In that situation]
197 C: statistic
198 N: Mm hm: [, ,
199 C: [Um he said that um (.) given the fact that I
200 would have radiotherapy and take some sort of hormone

201 (.) treatment a[fterwa:rds] u:m (.) eighty-five women=
202 N: [Yeah. Yeah.]
203 C: =out of a hundred (.) would be more or less safeguarded
204 under that a:[:nd an] >those conditions< .hh and if I=
205 N: [Mm: hm,]
206 C: =(.) had chemo I: er: it would then go up to ninety in a
207 hundred. .hh (.) U:m s[o th]at's °it°
208 N: [.tck] ↑So the chemo's adding a
209 sort of five perc[ent benefit]
210 C: [Five percent.] That's what- those are
211 the figures that he ga:ve me .hh a::nd tha- >you know<
212 I'm quite happy to take tho:se as bei:ng you know[:]
213 N: [Mm::]
214 C: th- th- you know wha- what's ac- accurate and everything
215 .hh it's just that I if there were some- some- something
216 e:lse that could help me make that decis[ion] but you=
217 N: [↑MM:::~:]
218 C: =see to me:: five percent (.) is not an awful lo::t,
219 N: No:. (0.2) N[o].
220 C: [>This is-< You know for the sake of ev- ev-
221 everythi:ng a:nd the fact that my sister's ha- you know
222 (.) made that decision >as well< .hh I'm earring to the
223 the si:de of um (.) not- no[t (doing it)]>and then sort=
224 N: [Yea:::h]
225 C: =of< #I:# and then (.) sort of facing up to the fact that
226 if in like three: or whatever year's time .hh I get it
227 and it comes back again then I will deal with it (0.2)
228 N: Mm[::
229 C: [you know in in the same respect as I am now.
230 N: Mm mm,
231 C: You know what I mea[n I wi]ll l- uh bu- ↑rather than
232 N: [Mm hm,]
233 C: it it's like an:: (.) to me it's like another insura:nce
234 (.) >sort of< u::m (.) p:olicy that may not I may not
235 need ↑↑anywa::y.=
236 N: =Yea::h. Yea:h. An- and tha:t's the:: .hhhh (.) er- hh
237 yea:h >I mean< you you've obviously got quite quite a
238 good ha:ndle on this you know the the purpo:se (.) ef-
239 effectively the cancer has been taken awa::y (.) and th-
240 the purpose of radiotherapy and hormone therapy is to
241 reduce the risk of it coming ba::ck [and] there's >never

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242 C: [Yeah]

243 N: =a< one hundred percent guarantee that it wo::n't (.)
244 unfortunately. .HHHHHHHHH So it sounds as though <what
245 he's saying> is that, (0.4) the risk of your cancer
246 coming ba:ck having ha:d radiotherapy and having some
247 hormone treatment (.) is fifteen perce:nt.

248 C: Mm:

249 N: And if he: (.) if he adds in chemotherapy (0.4) then it
250 will take it back to te:n perce:nt.

251 C: Mm (.) y[eah

252 N: [.tck but of cou::rse (0.4) having chemotherapy
253 isn't (.) going to give you a one ↑hundred perc[ent]=

254 C: [No:]

255 =guarantee: s[o]you cou:ld (.) potentially: (.) have=

256 C: [No.]

257 N: chemotherapy and it could still come ba::ck.

258 C: Mm:.

259 N: .HHHHH[HHH](.) I genuinely feel >w- we get< lo::ts of=
260 C: [(w-)]

261 N: =phone calls like this an #[e:#] ↓Yea::h. And I
262 C: [↑do you?]

263 N: a:nd (.) I genuinely think people are >kind of<
264 you know some people are of the >sort of opinion< tha:::t
265 (0.4) you know why have they even given me this choice I
266 will ha::ve it. I'll do ↑absolutely everything that I
267 ca:n and throw everythin' at it that I possibly ca:n.

268 C: Yeah.=

269 N: =Even if it's only five perce:nt. .hhhhh And lo:ts of
270 people (.) lo:::ts of women feel the way it sounds as
271 thou::gh >it really kind of< sounds a bit like you've got
272 your mi::nd made ↑up to be honest. .hh

273 C: I think I ha:ve.

274 N: ↓Yea:::h. .hhhh #e:# were (.) they fee:::l (.) you know
275 do I want to really put myself through a::ll of tha:t (.)
276 for five percent[t. And your sister has obviously kind=

277 C: [Yeah.]

278 N: =of been a:: (.) a sort of shining example really of
279 (.) >of of< how we:ll that's gone for her so ↑fa:::r.
280 .hhh (.) .tck I th[ink](0.2) what I'll ↑do: if you want=

281 C: [Yeah.]

282 N: =want is I'll I'll pop you on hold for a few minutes

283 while I have a hunt around and see what I can fi::nd,
 284 C: °'kay.°
 285 N: E:::rm,

CALLER MULTIPLE ISSUE 1 - TREATMENT OTHER

 286 C: Can I ask for some- s[or- can] I throw something else=
 287 N: [↑Yea::h]
 288 C: =into the mix. .hh I understand that that e::r one of
 289 the stages that can happen after breast cancer is
 290 it goes into your bo:::nes,
 291 N: Mm ↑hm,
 292 C: U::m now (.) >#is# that< ↑is it gonna I'm seeing- I I'm
 293 seeing the oncologist tomorrow. Is i::t >could it be<
 294 feasible to ask for some sort of bro- ↑brone? (.) Bo:ne
 295 scan of some descript[ation]o:::r would that help?
 296 N: [↓mm:::]

NURSE RESPONSE - VERBAL INFORMATION

 297 N: Do y- y[ou you you] ↑E:::m (0.4) you could do you you
 298 C: [°anything?°]
 299 N: could, you could a::sk about i::t. It's no::t it's only
 300 going to tell you: (.) wh- w- what your bones look like
 301 on that da::y (0.4) .hhh the wa:y that >do you
 302 understand< the way that cancer (.) comes ba::ck.
 303 (.)
 304 C: No, not f'reall[yf,
 305 N: [Yea:h. .hh Wha- what ha::- what would if
 306 it (.) ever came ba:ck, it what would happen is that it
 307 would be because a microscopic cell had been left behind.
 308 (.)
 309 C: O[h okay.
 310 N: So (.) either left behind in the same area where it was
 311 in the first place. o:[:::r] (.) it's travelled. A:nd=
 312 C: [°Yea°]
 313 =and gone to the, (0.4) to somewhe:re like the bo:::nes.
 314 C: O[h okay.
 315 N: [It may no] be >but the< bones is the most common
 316 place for it to go::
 317 C: Ri::ght.

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318 N: .tck .hh And and begun to grow agai:n. .hhh ↑So::: (0.5)
319 at this sta::ge lookin' at the lymph no::des (.) is
320 is >the sort of< (0.4) be::st way of picking up whether
321 or not it's likely to spread because that is the first
322 place it would travel to: if it was going to travel.
323 C: ↑Also I ha:d I elected to have um reconstructive surgery
324 N: Mm hm,
325 C: which he was quite pleased about the surgeon was quite
326 pleased about because he said it would give him an
327 opportunity to take mo:re away (.) from what (.) wa:s (.)
328 you know the the just the actual (e[r: the lump?])
329 N: [Yea::h yeah]
330 N: Yeah.
331 C: So on that basis then they would've taken out a whole
332 load mo:re,
333 N: Ye[a:h
334 C: [Just t[o be] on the safe side.
335 N: [Yeah]
336 N: I mean whenever they remove a lump they always remo::ve
337 (.) a margin of healthy tissue a[nyw]a:y t[o try]=
338 C: [Yea] [Yea::h]
339 N: =and ensure that >but it sounds as though< like he's
340 going to take even mo:re than tha::t
341 C: Yeah.
342 N: .hhh So agai::n that's a little bit of a sort of a belt
343 and braces for you:: if you l[ike] a bit of an=
344 C: [Yeah]
345 N: =insurance policy that they'll have taken awa:y
346 .h[h Qui]te a large area of tissue and hopefully have
347 C: [Yeah.]
348 N: go:ttten any of those microscopic cells. >So those are<
349 cells that are too small to be seen with the naked eye
350 when they're in doing an operation .hh but (.) equally
351 too small to be picked up on a sca:n.
352 C: Ri:ght.
353 N: So,
354 (0.6)
355 C: M[m:
356 N: [Tha::t's why:: we give these extra treatments
357 (0.6) to try and (.) to irradiate that area?
358 C: ↓Mm,

359 N: So that if there's a microscopic cell they've left behind
360 that will be taken care of. And that is why they (.)
361 they might think about adding in chemotherapy.=Now if
362 your lymph nodes are clear (.) and it was all confined
363 to that area and you had a clear margin when they took
364 it away and they also >think that they're< going to
365 take a bit more away, .hh it's pretty unlikely that
366 that cancer will have (.) traveled (.) >or there's<
367 and pretty unlikely that it's ever going to come back.

368 C: Mm:

369 N: but, (0.4) as I say there's (.) >there is never< a one
370 hundred percent guarantee. [#Er:# #e#] So: you could=
371 C: [↑Oh yeah (no no) .] [no okay]

372 N: =could ask for a bone scan. (0.4) >I don't< they
373 I can't say that they would definitely give it to yah,
374 C: Mm:,

375 N: >B[ut wha- wh]at< (.) what a bone scan will tell you is=
376 C: [(And wha-)]

377 N: =what they could see: on that day in your bones.
378 C: Right.

379 N: And that (0.6) might mean that they saw absolutely
380 nothing, (.) no evidence of cancer and that would be
381 great, (0.6) >but it< it doesn't give you any
382 guarantees for the future.
383 (0.2)

384 C: Right ↑so: w- w- (0.4) would it be (.) >sort of< safe
385 to say then that at this point in time there probably
386 wouldn't be anything in my bones and probably, (.) if I
387 was thinking about having a bone scan it might >be better
388 to< have it in a year's time?

389 N: .HHHHHH

390 C: Would that be a bit more (.) practical.

391 N: Well I can't, (.) yeah >I mean I don't want< to >sort
392 of< start advising you to start [as]king for scans in a=
393 C: [No]

394 N: =year's because it (.) it [] may not may not be of any=
395 C: [No]

396 N: =real benefit but yes it's safe to say that it wouldn't
397 probably it would be unlikely to show anything at this
398 stage th[at's] probably why they're not offering you one=
399 C: [Mm,]

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400 N: because they don't think it would really show anything.
401 C: Mm,
402 N: The::re.
403 C: yeah,
404 N: Because (0.4) the lymph nodes are clear. I[t's]unlikely=
405 C: [Yeah]
406 N: =that cancer has gone >anywhere else< because it it would
407 show up there fi[rst.]
408 C: [°Yea:°]
409 C: >I could< always >I mean< if if I did if they wouldn't
410 give it to me and I re[ally] wanted one I could always=
411 N: [↑Mm:]
412 C: =take i[t privately anyway (?)
413 N: [.hhh e:: you could do. You could do::.. but, (0.4)
414 I thi:nk (1.2) the kinnda it's no:t just about them
415 saying oh we wo:n't pay for it it it's also about what
416 benefit does it ha::ve,
417 C: Ye.
418 N: At the end of the da::y..h[h And] it (0.5) you kno::w=
419 C: [°Okay°]
420 N: =(.) I mean I don't I do:n't know this for sure but I
421 wo- I'm guessing there's probably some bit of (.) bit of
422 work out the::re some piece of resea::rch that sa::ys .hh
423 for women who have no evidence of cancer in the lymph
424 no:des and have a:: sma::llish (.) lump confined to the
425 brea:st that have X amount of treatment (0.4) having a
426 bone sc:an (.) shows no overall benefit in th[eir] =
427 C: [Yeah]
428 N: =survival in the lo:ng ter:m.=
429 C: Yes (.) yes [°I know°
430 N: [And equally (0.4) you:'re given some
431 radioactive material when you have a bone scan so there
432 is a small ↑risk in having one as well. >And it is<
433 sma::ll it's negligible.
434 C: Mm::
435 N: And often the benefit of (.) of tha:t sca:n (.) will be
436 to outweigh that risk but if they can't see any clear
437 benefit to that sc:an (.) they're not going to put you at
438 that risk a[n,] so it's not always about co::st either.
439 C: [No]
440 C: No [o-]

441 N: [And] that that's just >kind of< for your information
 442 re[ally.]
 443 C: [(Okay]

CALLER MULTIPLE ISSUE 2 - SECOND OPINION ABOUT TREATMENT

 444 C: Can I- >sorry< can I ask you something e:lse?
 445 N: Mm[:,
 446 C: [My sister didn't get o:n with (.) Tamoxifen, A[nd]
 447 N: [Mm hm,]
 448 C: she's now taking the other one or had taken the other
 449 one >was it Amoxin?< Or wa- is it,
 450 N: E:::rm (0.4) #A::#rimidex?
 451 C: Arimidex. That's i[t.] Arimidex. †U::m e- oo- (.) she=
 452 N: [Yea:h]
 453 C: =strongly advises me to a::sk for Arimidex r[ath]er=
 454 N: [Mm:]
 455 C: than um (.) Trimox >whatever the other< one i:s.
 456 N: Mm hm,
 457 C: Um would you wou- >h- how how< d[o you feel abou-

NURSE DATA GATHERING

 458 N: [.tck H- how o::ld are
 459 you if you don't mind me ask[ing
 460 C: [I'm fifty eight.
 461 N: And have you had the menopause?
 462 C: W- u::[m
 463 N: [>Have you been thr[ough °menopause°<
 464 C: [I don't really kno::w. Um
 465 £↑that sounds so pathetic doesn't i[t£
 466 N: [No::.
 467 C: U::m (.) I sort of- I think s- I don't
 468 kno::[w I might] still be having it. I don't kno:w.
 469 N: [.HHH wul-]

NURSE RESPONSE - VERBAL INFORMATION

 470 N: Oka::y the the reason I'm asking they can they can
 471 che::ck don't worry they can do a a simple blood test to
 472 to che::ck and see where you are with th:at.

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473 C: Yeah
474 (0.4)

475 N: .hhhh the reason t- e::r hhhh Tamoxifen it depends how
476 o::ld was your sister you know you've >given her's< was
477 seven years ago: †what ha[ppens] is that tamoxifen is
478 C: [(wha-]
479 N: =e::r is (.) usually give::n (0.6) tamoxifen is a >kind
480 o:f< (0.4) good drug that's >that's given to lots< of
481 people basically bu::t .hhh (0.4) a few years ago a study
482 came ou:t (.) that sho:wed that in post-menopausal women,
483 C: Mm,
484 N: .hh Arimide::x (.) wa:s (.) slightly more effective.
485 C: Okay.
486 (0.4)

487 N: In te::rms of the side effe::cts and how people got on
488 with drugs we never really kno::w (0.4) er y- you may
489 feel because >you're her< si:sters and you know >you've
490 probably got< similar make up that that it ma:y go that
491 †way for y- for you as we:ll and and it's possible that
492 it mi::ght (.) >but it's< not a sort of definite
493 indicator that (.) you kno:w you will feel terrible on it
494 or that everybody does.
495 C: Ri::ght ok[ay
496 N: [E::m (.) bu::t (0.4) yeah >there was< there
497 was a sort of a a study came out and I can sho:w guide you
498 to so::me (.) information about this on on cancer
499 resea:rch's website or I can post it to you if you like.
500 C: †Okay.
501 N: .hhh but there was a study (.) do::ne sort of comparing
502 the benefits of these different types of of hormone
503 treatments >and it was< sho:::wn that (.) a group of drugs
504 called aromatase inhibitors which is wha::t (.) arimide:x
505 is (0.4) .tch we:re ever so slightly more effe:cti:ve
506 in post-menopausal women. (0.4)

507 C: Okay,
508 N: .hhh but not so effective in, (0.4) pre-menopausal women.
509 C: Mm::
510 N: to the point actually that they don't give them (.) to
511 pre-menopausal women.
512 C: So what ha[ppens-
513 N: [PRE-]menopausal women usually always get

514 tamoxifen.
 515 C: O::h. Cause I I I judging by my vagueness I would
 516 definitely say that I'm sort of in the middle of it.
 517 N: R::ight,
 518 C: U::m so in which case then it would probably be the um,
 519 (0.6) fi[rst

NURSE RESPONSE – REFERRAL TO HCP AND REHEARSING

 520 N: [.HHH they they mi:ght offer it >to you< I would,
 521 (.) just have a discussion with them about it and [and]
 522 C: [Yeah]
 523 N: see what they're saying and, (.) >jus- just< say exactly
 524 what you've said to me: you k[no::w] (.) .hhh >my sister=
 525 C: [yea::h]
 526 N: had a bad experience< with i:t I'm >a bit wary< of it
 527 no::w (.) you kno:w I'm I'm wh- what is your advi:ce
 528 around tha::t.
 529 C: †Okay.

NURSE RESPONSE – VERBAL INFORMATION

 530 N: .HH E:::rm (.) er they essentially do the same thi::ng (.)
 531 do you understand wha- what they do::?
 532 C: N:::- no not really.
 533 N: Yeah wha- what they do is #e:::r# .hhh (1.8) #er# many
 534 breast cancers ultimately rely on oestrogen to gro:w
 535 C: Ri:[ght,
 536 N: [And what those drugs do is (.) switch o:ff oestrogen.
 537 C: Ri:ght.
 538 N: Very crudely (.) that's what they do::.. But between
 539 tamoxifen and something like arimide::x they do it and
 540 they definitely have there's a different mechanism
 541 involved in how they do tha:t.
 542 C: A::h right okay.
 543 N: .hh E:::m (0.4) but they essentially do the same thing.
 544 (0.6) e:::m and tha:t and that does mean some side effects
 545 which involve oestrogen and it is sometimes it's a bit
 546 like menopausal side effects hot flushe::s, (0.4) lots of
 547 people get some stiffne:ss and aching in the joi::nts
 548 tha:t tha:t type of stu:ff. †#E:::m# some people put on

Appendix J

549 a little bit of weight someti::mes.

CALLER MULTIPLE ISSUE 3 – DISCLOSURE ABOUT ANXETY

550 C: I have been suffering (.) er for quite a number of years
551 with u:m (.) um anxiety I m[ean] I do get >hot flushes=
552 N: [Mm::]
553 C: =occasionally< but I find that the: .hh anxiety u::m
554 levels have certainly you know (.) really (.) been the
555 problem with me::
556 N: Mm::, Mm::
557 C: U::m (.) but anyway.
558 (0.4)

NURSE DATA GATHERING

559 N: I mean have you had any sort of suppo:rt with tha::t?
560 (0.6)
561 C: No not really, (0.4) um no:: I just u::m I just take a
562 fe::w (.) homeopathic remedy things and u[m] (.)I just=
563 N: [Mm]
564 C: =try and do a little bit of wa:lki:ng and ju:st (.) just
565 try and get on with it cause a[t the] end of the day you=
566 N: [↑Mm::]
567 C: =know I just try and think to myself well it's just you:r
568 (.) brain just (.) playing tricks with you a:[:n- (.)]=
569 N: [↑Mm:::]
570 C: =just °well°
571 (0.2)
572 N: An- I I mean, (.) have you ever thought about sort of
573 talking to somebody about it.
574 C: Well I've (.) I've been to the doctor a couple of times
575 and he >sort of said< o::h well (.) you know you can eat
576 more yams and stuff like this and (.) do you know what I
577 mean I'm obviously not HRT is not (.) not going to be
578 recommended li[ke knowin]I've had reflexology: (.) over=
579 N: [Mm:::]
580 C: =a number of years do you know what I mea::n I[ve](.)=
581 N: [Mm::]
582 C: =dibbled and dabbled in stuff.
583 N: MM:,

584 C: But that's bee::n (.) th- that that is coping with it (.)
 585 in a way that I've just explained is the only thing
 586 th[at I've done]
 587 N: [Mm:, mm:, mm.]

NURSE RESPONSE - SUPPORT

 588 N: .tck I mean a::ll that sort of stuff is is grea::t >I
 589 mean< it's y- you kno::w it's sounds as though it has
 590 helped a bi:t. .hh I suppose what I was thinking is
 591 that if tha::t's something that's (.) been (.) on going
 592 (0.4) given what you're dealing with no::w (.) you kno::w
 593 i- it mi:ght be a time when you ↑may feel as though you
 594 need a bit more help and suppo:rt and (.) I would never
 595 suggest that tha:t's something that you need,.h[h_bu:]t,
 596 C: [Mm::,]
 597 C: What do you mean like antidepressant[ts.
 598 N: [↑No. (.) No. Like I
 599 mean like maybe just talking to something like a support
 600 group just talking to othe:r (.)ladies in a similar
 601 position it sounds as though you maybe had good support
 602 from your sister anywa:y and she's able to kind of (.)
 603 guide you a little bit being that she's been through
 604 i:t. .hh Bu::t (.) you kno::w thinking of somewhe::re that
 605 you might be able to just talk freely without fear of what
 606 (0.4) what that other person might thi::nk or >you
 607 kno:w<, .hh ofte:n >for example< people do:n't feel able
 608 to talk to family members and friends because it upse:ts
 609 ↑the::m.
 610 (0.2)
 611 C: Mm:: (.) I just think that it's just (.) u:::m (.) well I
 612 don't know it's just something which is, (0.4) so on
 613 go:ing I've lived with it for so many years n[ow] I::'ve=
 614 N: [Mm]
 615 C: =(.) I've just got used to it I suppo::se.
 616 N: Yeah (.) ↑yea::h and that's what happens people find their
 617 own coping mechanisms and and their own way of dealing
 618 with thi:ngs .hhh (.) you know (.) what I would say is if
 619 (.) if it wa::s something you wanted to sort of explore in
 620 terms of where could I get that type of support (.) we we
 621 could try and point you in the right direction and t[hat]

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622 C: [Okay]
623 N: I won't you know (.) don't feel you have to think about
624 that right no::w you can (.) phone us ba::ck and have
625 another cha::t about it.
626 C: °Okay°
627 N: You can certainly u:se us if you just (.) wa:nt to have a
628 cha:t about thi::ngs you don't need to have a specific
629 question to pho:ne u:s (.) .hh if you just need somewhere
630 to kinna offload about that and bounce your thoughts
631 around that that's fine a[s] we::ll (.) .hh because=
632 C: [Mm,]
633 N: it is a lo:t to cope with all this it's no:t (.) not easy.
634 C: ↓We::ll (0.4) it's you reach a point where you've
635 offloaded so much you kno:w on like my husba:nd you know
636 and it it just it's obviously wears people do:wn an-,
637 N: ↑Mm:::
638 C: And there's no sort of straight answers to stuff so that
639 you re[ach a] point where you just don't do it anymore.
640 N: [No:::]
641 N: Yea:::h,
642 C: Which is oka:y. Huh (.) °okay°
643 (0.4)

CALL CLOSING 1

644 N: Nea::h. ↑Well I'll leave it with ya.
645 some[thing to think] about
646 C: [↑Okay then yea::h] I can yeah I'll have a think
647 about that. [°Thank you°]

NURSE RESPONSE - BOOKLET OFFER

648 N: [Did you wan]t me to send you so::me some
649 written information abou::t (0.6) you know sort of
650 Tamoxifen and Arimidex all tha::t ki[nd of thing].
651 C: [Yea::h would you do
652 that.
653 N: Yea:::h,
654 C: That would be grea::t.
655 N: Did my colleague take your address when you phoned earlier
656 [(?)]

657 C: [Yea::h I've got I'm on your system somewhere I think.
658 (0.2)
659 C: Have you g[ot my (.) er post co:de.
660 N: [E::::r]
661 (0.4)
662 N: Bear with me (2.0) oh here we are ((caller's address)),
663 C: T[hats it.
664 N: [((location name and postcode))
665 C: †Where are you: ba:sed?
666 N: I'm in Lon:don.
667 C: Ah::
668 N: But I'm a long way from †home.
669 C: †Are you?†
670 N: Ha ha ha I'm only kid[ding
671 C: [I would never have guessed[ha ha ha]
672 N: [ha ha ha]
673 N: Yea(h)h. We do have some nurses based in Glasgow as
674 we:ll but I'm af- afraid I'm a hybrid o:f (.) of the two:.
675 C: O::h
676 N: [.hhhh] E::::rm (.) but yeah you c- absolutely do do
677 phone back and you know if there's anything in that
678 information that doesn't make se::nse or, >[you]know<=
679 C: [Yea.]
680 N: =throws up more questions that's fine just give us
681 a call and w[e'll be happy to chat it through
682 C: [(???) it's a good idea to have a little chat
683 about the: anxiety and stuff.
684 N: †Yea::h see how you go- I me[an i-]it's just a thou:ght=
685 C: [°Yea.°]
686 N: =you kno[w gi]ven tha:t (.)this wi:ll add into that I'm=
687 C: [Yeah]
688 N: =su::re you know no- no- nobody gets diagnosed with cancer
689 without feeling a little bit worried about it.
690 C: Yea::h. Just a bit. †huh huh huh huh huh
691 N: Mm:: huh uh

CALL CLOSING FINAL

692 C: †Oh: thank you so much for ringing me ba:ck.
693 N: You:'re welcome. Are you happy for me just to keep a very
694 brief (.) no::te of what we've talked abou[t. Tha- tha]t=

Appendix J

695 C: [↑Of course.]
696 N: =just helps if you do phone ba:ck and it's
697 i[t's all confidential.
698 C: [No no do whatever you- no whatever you want.
699 N: Alright well you take care of yourse::lf
700 C: Thank you very mu:ch
701 N: Thanks buby
702 C: Bye:
---End of Call.

Appendix K - Caller problems volunteered throughout both parts of the call (patients)

	PI to ISO	MI1	MI2	MI3	PI to nurse	MI 1	MI2	MI3	MI4	MI5	MI6	MI7
TREATMENT												
~ Treatment info (general)	n: 14	n: 1	n: 0	n: 0	n: 10	n: 7	n: 10	n: 4	n: 3	n: 1	n: 0	n: 0
~ Second opinion	n: 1	n: 0	n: 0	n: 0	n: 6	n: 2	n: 2	n: 1	n: 2	n: 0	n: 0	n: 0
~ Side effects	n: 1	n: 0	n: 0	n: 0	n: 0	n: 2	n: 3	n: 1	n: 1	n: 0	n: 1	n: 0
~ Pain dosage	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
~ Other	n: 2	n: 0	n: 0	n: 0	n: 3	n: 0	n: 1	n: 0	n: 1	n: 0	n: 0	n: 0
Total no. treatment issues	n: 18 %39.1	n: 1 %2.2	n: 0 -	n: 0 -	n: 19 %35.8	n: 11 %20.8	n: 16 %30.2	n: 6 %11.3	n: 7 %13.2	n: 1 %1.9	n: 1 %1.9	n: 0 -
SYMPTOMS												
~ Advice	n: 1	n: 0	n: 0	n: 0	n: 5	n: 1	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
~ Concerns	n: 5	n: 1	n: 1	n: 0	n: 9	n: 5	n: 4	n: 0	n: 0	n: 1	n: 0	n: 1
Total no. symptom issues	n: 6 %13	n: 1 %2.2	n: 1 %1.9	n: 0 %	n: 14 %26.4	n: 6 %11.3	n: 4 %7.5	n: 0 -	n: 0 -	n: 1 %1.9	n: 0 -	n: 1 %1.9
UNCERTAIN FUTURE MATTERS												
~ Prognosis	n: 1	n: 0	n: 0	n: 0	n: 2	n: 2	n: 0	n: 1	n: 0	n: 1	n: 0	n: 0
~ Progression	n: 0	n: 0	n: 0	n: 0	n: 1	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
~ Recurrence	n: 1	n: 1	n: 1	n: 0	n: 1	n: 1	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
~ EOL	n: 0	n: 0	n: 0	n: 0	n: 0	n: 3	n: 1	n: 0	n: 0	n: 0	n: 0	n: 0
Total no. uncertain future issues	n: 2 %4.3	n: 1 %2.2	n: 1 %	n: 0 %	n: 4 %7.5	n: 6 %11.3	n: 1 %1.9	n: 1 %1.9	n: 0 -	n: 1 %1.9	n: 0 -	n: 0 -
PSYCHOSOCIAL ISSUES												
~ Emotional Support	n: 1	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0

Appendix K

~ Wants to talk	n: 1	n: 0	n: 0	n: 0	n: 4	n: 1	n: 0	n: 0	n: 0	n: 0	n: 1	n: 0
~ Disclosure of a trouble	n: 0	n: 0	n: 0	n: 0	n: 0	n: 3	n: 2	n: 1	n: 0	n: 1	n: 0	n: 1
~ Support available	n: 1	n: 1	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
~ Support solicited	n: 0	n: 4	n: 0	n: 1	n: 0	n: 0	n: 0	n: 1	n: 0	n: 0	n: 0	n: 0
Total no. psych issues	n: 3 %6.5	n: 5 %10.9	n: 0 %	n: 1 %1.9	n: 4 %7.5	n: 4 %7.5	n: 2 %3.8	n: 2 %3.8	n: 0 -	n: 1 %1.9	n: 1 %1.9	n: 1 %1.9
MEDICAL INFORMATION (GENERAL)												
~ Cancer Site Information	n: 3	n: 1	n: 0	n: 0	n: 3	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
~ Booklet Request	n: 5	n: 1	n: 0	n: 0	n: 4	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
~ Medical Terminology	n: 3	n: 0	n: 0	n: 0	n: 3	n: 2	n: 1	n: 1	n: 0	n: 0	n: 0	n: 0
Total no. medical info	n: 11 %23.9	n: 2 %4.3	n: 0 %	n: 0 %	n: 10 %18.9	n: 2 %3.8	n: 1 %1.9	n: 1 %1.9	n: 0 -	n: 0 -	n: 0 -	n: 0 -
FINANCE	n: 3 %6.5	n: 1 %2.2	n: 1 %2.2	n: 1 %2.2	n: 0 -	n: 1 %1.9	n: 1 %1.9	n: 4 %7.5	n: 0 -	n: 0 -	n: 0 -	n: 0 -
OTHER	n: 3 %6.5	n: 1 %2.2	n: 0 %	n: 0 %	n: 2 %3.8	n: 3 %5.7	n: 2 %3.8	n: 1 %1.9	n: 0 -	n: 0 -	n: 0 -	n: 0 -
DOESN'T SAY	n: 2 %4.3											
TOTAL MULTIPLE ISSUES		n: 12 %26.1	n: 3 %6.5	n: 1 %2.2		n: 33 %71.7	n: 27 %50.9	n: 15 %28.3	n: 7 %13.2	n: 5 %9.4	n: 2 %3.8	n: 1 %1.9

Legend: PI to ISO (problem 1 presented to the information support officer or ISO); MI1,MI2 (no. of multiple issues volunteered/discussed in the ISO part of the call); PI to nurse (problem 1 presented to the nurse); MI 1,MI2, MI3, MI4, MI5 (no. of multiple issues volunteered/discussed in the nurse part of the call).

Appendix L - Caller problems volunteered throughout both parts of the call (carers)

	PI to ISO	MI1	MI2	PI to nurse	MI 1	MI2	MI3	MI4	MI5
TREATMENT									
~ Treatment info (general)	n: 9	n: 2	n: 1	n: 6	n: 8	n: 5	n: 1	n: 2	n: 0
~ Second opinion	n: 2	n: 0	n: 0	n: 2	n: 2	n: 0	n: 1	n: 0	n: 1
~ Side effects	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 1	n: 0	n: 0
~ Pain Dosage	n: 1	n: 1	n: 0	n: 2	n: 2	n: 0	n: 0	n: 0	n: 1
~Other	n: 2	n: 0	n: 0	n: 2	n: 0	n: 1	n: 0	n: 0	n: 0
Total no. treatment issues	n: 14 % 34.1	n: 3 % 7.3	n: 1 %2.3	n: 12 % 26.1	n: 12 % 26.1	n: 6 % 13	n: 3 % 6.5	n: 2 %4.3	n: 1 %2.2
SYMPTOM ISSUES									
~ Advice	n: 3	n: 0	n: 0	n: 4	n: 1	n: 0	n: 0	n: 0	n: 0
~ Concerns	n: 4	n: 0	n: 0	n: 4	n: 0	n: 1	n: 0	n: 0	n: 0
Total no. symptom issues	n: 7 % 17.1	n: 0	n: 0	n: 8 % 17.4	n: 1 % 2.2	n: 1 %2.2	n: 0	n: 0	n: 0
UNCERTAIN FUTURE MATTERS									
~ Prognosis	n: 1	n: 1	n: 0	n: 4	n: 2	n: 2	n: 0	n: 0	n: 0
~ Progression	n: 4	n: 1	n: 0	n: 5	n: 2	n: 4	n: 2	n: 0	n: 0
~ Recurrence	n: 1	n: 0	n: 0	n: 1	: 0	n: 0	n: 0	n: 0	n: 0
~ EOL	n: 1	n: 0	n: 0	n: 2	n: 3	n: 0	n: 1	n: 0	n: 0
Total no. uncertain future issues	n: 7 % 17.1	n: 2 % 4.9	n: 0	n: 12 % 26.1	n: 7 % 15.2	n: 6 % 13	n: 3 % 6.5	n: 0	n: 0
PSYCHOSOCIAL ISSUES									
~ Emotional Support	n: 2	n: 0	n: 0	n: 3	n: 0	n: 1	n: 0	n: 0	n: 0

Appendix L

~ Wants to talk	n: 4	n: 1	n: 0	n: 2	n: 4	n: 2	n: 1	n: 0	n: 0
~ Disclosure of a trouble	n: 0	n: 0	n: 0	n: 0	n: 2	n: 0	n: 1	n: 0	n: 0
~ Support available	n: 1	n: 1	n: 0	n: 1	n: 3	n: 1	n: 0	n: 0	n: 0
~ Support solicited	n: 0	n: 9	n: 1	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
Total no. psych issues	n: 7 % 17.1	n: 11 %26.8	n: 1 %2.3	n: 6 %13.6	n: 9 %19.6	n: 4 % 8.7	n: 2 % 4.3	n: 2 %4.3	n: 0
MEDICAL INFORMATION (GENERAL)									
~ Cancer Site Information	n: 2	n: 0	n: 0	n: 3	n: 2	n: 1	n: 0	n: 0	n: 0
~ Booklet Request	n: 3	n: 1	n: 0	n: 3	n: 0	n: 0	n: 0	n: 0	n: 0
~ Medical Terminology	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
Total no. medical info	n: 5 % 12.2	n: 1 %2.2	n: 0	n: 6 % 13	n: 2 % 4.3	n: 1 % 2.2	n: 0	n: 0	n: 0
FINANCE	n: 0	n: 0	n: 1 %	n: 0	n: 0	n: 0	n: 1 %	n: 0	n: 0
OTHER	n: 1 % 2.4	n: 2 %4.9	n: 0 %	n: 2 % 4.3	n: 2 % 4.3	n: 0 -	n: 1 %1.9	n: 0 -	n: 0 -
DOESN'T SAY	n: 1 %2.3	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0	n: 0
TOTAL MULTIPLE ISSUES		n: 19 %44.2	n: 3 %7		n: 33 %71.7	n: 18 %39.1	n: 10 %21.7	n: 4 %8.7	n: 1 %2.6

Legend: PI to ISO (problem 1 presented to the information support officer or ISO); MI1, MI2 (no. of multiple issues volunteered/discussed in the ISO part of the call); PI to nurse (problem 1 presented to the nurse); MI 1,MI2, MI3, MI4, MI5 (no. of multiple issues volunteered/discussed in the nurse part of the call).

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