Doctor-Patient Communication in Head-and-Neck Cancer Follow-up Consultations

The role of the Distress Thermometer and Problem List

Cancer survivors often suffer from psycho-social problems as a consequence of side effects of treatment and fear of recurrence of the disease. Although there is wide consensus that this kind of distress has a negative effect on health and healing, the discussion of emotional problems does not routinely occur in follow-up cancer consultations.

This thesis investigates the interaction between doctors and patients in a corpus of scheduled head-and-neck cancer follow-up consultations in a cancer centre in The Netherlands, with a focus on the effects of the introduction of the Distress Thermometer and Problem List (DT+PL) as a tool to further the discussion of psychosocial distress.

The multi-method design of the study, including insights from ethnography of communication and discourse analysis (more specifically conversation analysis and linguistic pragmatics), combines interviews with doctors and patients reflecting on the follow-up head-and-neck cancer consultation with a qualitative analysis of video-recorded consultations and descriptive quantitative data on discursive patterns that surfaced in the interactions. This broad design made it possible to trace not just what issues are discussed in the consultation and how frequently they are discussed, but also how the participants co-construct the interaction, what contextual parameters influence this, how the DT+PL affects all this, and how doctors and patients view the follow-up consultation and the DT+PL.

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Manon van der Laaken

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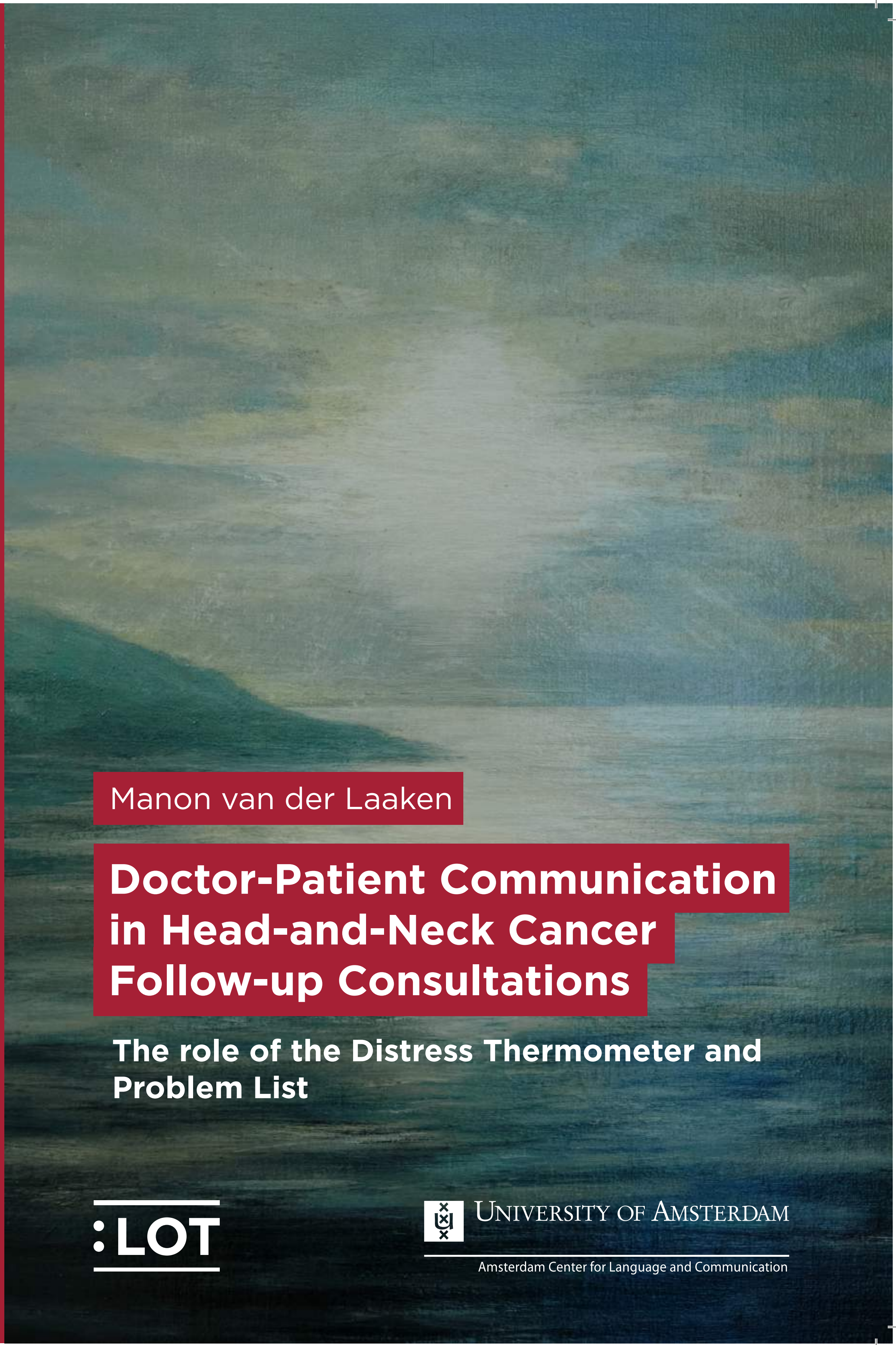

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Author contributions

Chapter 3
This chapter is an adapted version of:
Van der Laaken, M. & Bannink, A. (2020). Openings in follow-up cancer consultations: The 'How are you?' question revisited. *Discourse Studies 22(2)*: 205-220.

Van der Laaken analysed the data and wrote the article, and Bannink supervised the process and edited the paper, giving feedback and contributing suggestions for improvement.

Chapter 4
Elin Derks, MA suggested 'orientation to wellness' as a topic for this chapter. Van der Laaken analysed the data and wrote the paper, and Elin Derks and Frans Hilgers provided feedback and suggestions for improvement on earlier versions of this chapter.

Chapter 5
This chapter is an adapted version of:
Van der Laaken, M., Bannink, A. & Van den Brekel, M. (2020). Topicalizing psychosocial distress in cancer follow-up consultations: An exploration of the interactional effects of discussion tools. *Cogent Arts & Humanities 7(1)*: 1812866.

Van der Laaken analysed the data and wrote the article, Bannink supervised the process and edited the paper, giving feedback and contributing suggestions for improvement, Van den Brekel gave feedback and suggestions for improvement.

Chapter 7
This chapter is an adapted version of:
Van der Laaken, M. & Bannink, A. (in press). De discursieve constructie van emotionele problemen in het follow-up consult van hoofd-hals-kankerpatiënten. *Tijdschrift voor Taalkunde*.

Van der Laaken analysed the data and wrote the article, and Bannink supervised the process and edited the paper, giving feedback and contributing suggestions for improvement.

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Preamble

The project which forms the basis of this thesis was first conceived of in 2011, in an informal meeting between Olga Fischer, Anne Bannink and Frans Hilgers. The research proposal was developed by Elin Derks, M.A. at the request of and in collaboration with a team of oncologists at the Nederlands Kankerinstituut-Antoni van Leeuwenhoek ('Netherlands Cancer Institute-Antoni van Leeuwenhoek'; NKI henceforth), a tertiary care centre specialised in the treatment of and research into cancer in The Netherlands. In the first decade of the 21st century, awareness had taken hold among the medical profession and medical management that structural attention needs to be paid to psychosocial distress in post-cancer care (e.g., Integraal Kankercentrum Nederland, 2010). One of the ways in which it was thought this could be achieved was through the use of the Distress Thermometer and Problem List (DT+PL), a tool designed by the National Comprehensive Cancer Network (NCCN) to monitor psychosocial distress (NCCN, 1999; Tuinman et al., 2008). It was recommended that this tool be used in all hospitals in The Netherlands as a discussion instrument to further the discussion of psychosocial distress (Medicalfacts.nl, 2009; Integraal Kankercentrum Nederland, 2010). Before rolling it out, the head-and-neck oncologists at the NKI wanted to know whether the implementation of this tool would make sense in the context of follow-up head-and-neck cancer consultations.

The project was envisaged to find out what happens if the DT+PL is used in follow-up head-and-neck cancer consultations from a discursive perspective: How does it impact the interactional organisation of the consultation? Does it stimulate the discussion of psychosocial concerns? Does it affect the consultation in other ways? A number of years into the project, after the project proposal was approved, permission from all the relevant bodies was obtained, informed consent was granted by all the participants, all the technical problems were solved, and the data had been gathered, personal circumstances led Elin Derks to choose a different career path. The project needed a new person to carry it out, and in 2015 I was invited to take over the project, next to my duties as a lecturer of linguistics. The results lie before you.

Introduction, theoretical perspectives and background of the data

1.0 Introduction

A large body of research has shown that a considerable number of cancer patients and cancer survivors suffer from a wide range of psychosocial concerns which are related to the disease (see e.g., Arora, 2003; Boyes et al., 2011; Epstein & Street, 2007; Gil et al., 2012; Hartung et al., 2017; Hewitt et al., 2006; Integraal Kankercentrum Nederland, 2010; Mehnert et al., 2018; Mitchell et al., 2012; NCCN, 1999; Trask, 2004). Hewitt et al. (2006) state that some cancer survivors "suffer permanent and disabling symptoms that impair normal functioning" (p. 2), including psychological distress, which is confirmed e.g., by Trask (2004), who states that around 30% of patients suffer from "psychological disorders (i.e., anxiety, depression, adjustment disorders)" (p. 80). Similar figures were presented by e.g., Boyes et al. (2011), Hartung et al. (2017) and Mitchell et al. (2012), while Integraal Kankercentrum Nederland (2010) states that 25-50% of cancer patients experience so much distress during and after treatment and follow-up "that referral to a specialised psychosocial and or (para) medical caregiver is warranted" (p. 1, *author's translation*). Figures vary with types of cancer, with head-and-neck cancer patients seeming to be particularly badly affected by the disease (Gil et al., 2012).

Since psychosocial distress has been shown to have a negative effect on health and healing (see e.g., House, 2015; Otto-Meyer, 2019; Powell et al., 2013; Shi et al., 2018), it is widely seen as important that psychosocial issues are detected and discussed during the follow-up cancer consultation (see e.g., Arora, 2003; Epstein & Street, 2007; Grootenhuis & Maes, 2009; Higginson & Carr, 2001; Integraal Kankercentrum Nederland, 2010). However, this does not routinely happen. Research shows that physicians tend to focus on biomedical concerns and to steer away from psychosocial topics when they communicate with their patients (see e.g., Arora 2003; Beach et al., 2005; Cameron et al., 2015; Detmar et al., 2000; Ford et al., 1996; Granek et al., 2018; Gulbrandsen et al., 1997; Maguire 1999, 2002; Werner et al., 2012, Zhou et al., 2015). Doctors and patients also seem to be at cross purposes: Ford et al. (1996) found that "some patients did disclose their psychosocial concerns, but in the majority of cases these were not pursued by clinicians" (p. 1517), while Detmar et al. (2000)

found that in their study “all the physicians indicated that they generally defer to their patients in initiating discussion of psychosocial issues”, but that one in four patients were only willing to discuss psychosocial issues “at the initiative of their physician” (p. 3295). All in all, the ‘voice of medicine’ and the ‘voices of patients’ lifeworld’ do not seem to meet (Clark & Mishler, 1992).

As a consequence of the growing consensus that the detection, discussion and treatments of patients’ psychosocial issues are important in the follow-up of cancer survivors (see e.g., Arora, 2003; Epstein & Street, 2007; Grootenhuis & Maes, 2009; Higginson & Carr, 2001; Integraal Kankercentrum Nederland, 2010), guidelines have been developed for the detection of the need for psychosocial care (e.g., Cohen et al., 2016; Integraal Kankercentrum Nederland, 2010). In The Netherlands, the Integraal Kankercentrum Nederland (‘Integral Cancer Centre Netherlands’, IKNL), in collaboration with the Nederlandse Vereniging voor Psychosociale Oncologie (‘Dutch Society for Psychosocial Oncology’; NVPO) and the Koningin Wilhelmina Fonds-Kankerbestrijding (‘Queen Wilhelmina Foundation for the Fight against Cancer’; KWF), developed and published a national guideline for the detection and screening of psychosocial distress (*Landelijke richtlijn detecteren behoefte psychosociale zorg*; see Integraal Kankercentrum Nederland, 2010), with the aim to improve the detection and treatment of psychosocial distress in (ex-) cancer patients, and improve their quality of life. By 2016 it had been implemented in almost all the hospitals in The Netherlands for at least one group of patients (Van der Linden & Hoekstra-Weebers, 2016). This guideline uses the definition developed by the US National Comprehensive Cancer Network to define distress: “Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling such as depression, anxiety, panic, social isolation and existential and spiritual crisis” (NCCN, 2015). To determine when distress becomes ‘problematic’, and at what point patients need extra help and care, ‘easy-to-administer’ tools have been developed and introduced for screening psychosocial distress (Hewitt et al., 2006; Krebber et al., 2016; NCCN, 1999; Trask, 2004).[1]

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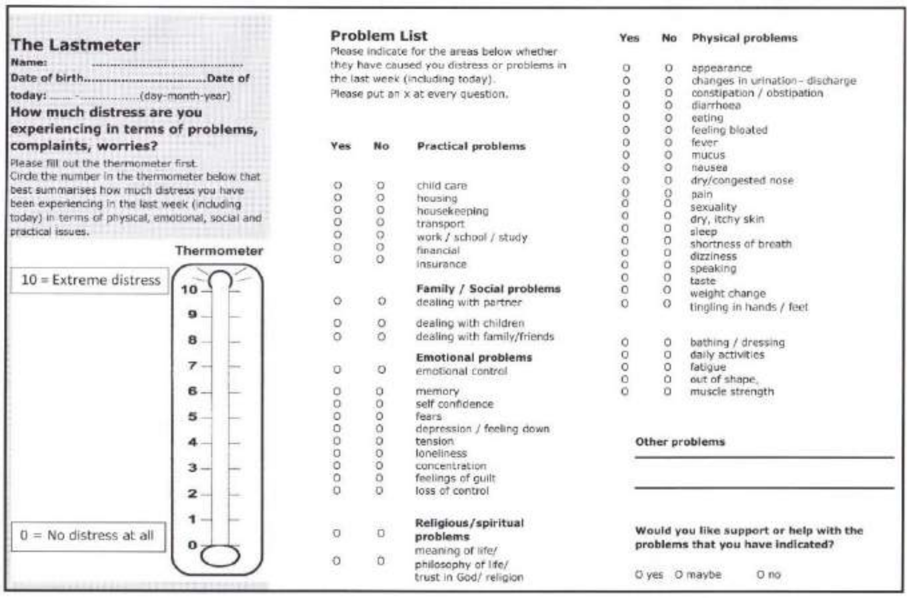
[1] Recently, the COVID19 pandemic has renewed and intensified interest in the use of health-related quality-of-life (HRQL) screening instruments and other patient reported outcome measures (PROMs) to safely monitor outpatients at a distance, via telemedicine (see e.g., Bateman et al., 2021; Pendolino et al., 2020; Pompili et al., 2021; Strohl et al., 2020).

1.1 The DT+PL as a measuring/screening tool

The DT+PL has been developed by the NCCN, USA as an instrument for screening cancer patients and cancer survivors for physical and psychosocial distress, and determining the need for referral to specialist caregivers (Holland & Bultz, 2007; NCCN, 1999; Tuinman et al., 2008). It was selected as the most suitable screening instrument for psychosocial distress, and strongly recommended for use in Dutch medical care in the guideline *Detecteren behoefte psychosociale zorg* (Integraal Kankercentrum Nederland, 2010; Medicalfacts.nl, 2009). This instrument has since been implemented in many hospitals.

The DT+PL consists of a form that patients are asked to fill out (see Figure 1). It is recommended that patients fill out the DT+PL before every follow-up consultation. They then hand it in to the attending physician or nurse for it to be discussed immediately and included in the patient's medical file.



The Lastmeter

Name: ....

Date of birth...................................**Date of today:** ....-...................(day-month-year)

How much distress are you experiencing in terms of problems, complaints, worries?

Please fill out the thermometer first.
Circle the number in the thermometer below that best summarises how much distress you have been experiencing in the last week (including today) in terms of physical, emotional, social and practical issues.

Thermometer

10 = Extreme distress

0 = No distress at all

Problem List
Please indicate for the areas below whether they have caused you distress or problems in the last week (including today).
Please put an x at every question.

Yes	No	**Practical problems**
○	○	child care
○	○	housing
○	○	housekeeping
○	○	transport
○	○	work / school / study
○	○	financial
○	○	insurance
		Family / Social problems
○	○	dealing with partner
○	○	dealing with children
○	○	dealing with family/friends
		Emotional problems
○	○	emotional control
○	○	memory
○	○	self confidence
○	○	fears
○	○	depression / feeling down
○	○	tension
○	○	loneliness
○	○	concentration
○	○	feelings of guilt
○	○	loss of control
○	○	**Religious/spiritual problems**
○	○	meaning of life/ philosophy of life/ trust in God/ religion

Yes	No	**Physical problems**
○	○	appearance
○	○	changes in urination - discharge
○	○	constipation / obstipation
○	○	diarrhoea
○	○	eating
○	○	feeling bloated
○	○	fever
○	○	mucus
○	○	nausea
○	○	dry/congested nose
○	○	pain
○	○	sexuality
○	○	dry, itchy skin
○	○	sleep
○	○	shortness of breath
○	○	dizziness
○	○	speaking
○	○	taste
○	○	weight change
○	○	tingling in hands / feet
○	○	bathing / dressing
○	○	daily activities
○	○	fatigue
○	○	out of shape,
○	○	muscle strength

Other problems

____

____

Would you like support or help with the problems that you have indicated?

○ yes ○ maybe ○ no

Figure 1
The translated version of the 'Lastmeter', the Dutch version of the DT+PL. For the original Dutch version that was used in the project, see Appendix 1.[2]

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[2] There is also an online version available, which patients can share with their caregiver: http://www.lastmeter.nl/

The form is divided into two sections: the Distress Thermometer (in the left-hand column) and the Problem List (in the two columns on the right). On the Distress Thermometer, patients can indicate their general level of distress – which is specified as including physical, emotional, social and practical problems – over the past week including ‘today’, where 0 indicates no distress, and 10 indicates extreme distress. It is generally accepted that some level of mental distress is to be expected in cancer patients and survivors, and both patients (see e.g., Maguire, 2002) and oncologists seem to share this view (see e.g., Granek et al., 2018). One of the functions of the DT+PL is to establish when distress becomes ‘problematic’, and patients need to be referred to specialist care. Research into the validity of the DT+PL as a screening instrument of distress has established that for detecting problematic distress in cancer patients in The Netherlands, the cut-off score for the Distress Thermometer is 5 (Tuinman et al., 2008).[3] If patients score 5 or higher, this indicates elevated, problematic distress; such patients significantly more often indicate they want to be referred to specialist psychosocial care (see Integraal Kankercentrum Nederland, 2010).

The Problem List features 47 possible problems that the patient might have. They are divided into practical problems, ranging from childcare to insurance (7 items); family/social problems (3 items); emotional problems, such as fears, depression and loneliness (10 items); religious/spiritual problems (2 items); and physical problems, ranging from sexuality to nausea (25 items). The patient is asked to indicate which of these items have been problematic in the last week, yes or no. There is also an open question on the Problem List, which gives patients the opportunity to enter any ‘other problems’ they have been suffering from, which do not appear on the Problem List. The last question on the DT+PL is whether the patient would like support or help with the problems they have indicated.

1.2 The DT+PL as a discussion tool

Screening tools such as the DT+PL have been widely implemented – although more among nursing and reintegration staff than among physicians – as a means of facilitating both the monitoring and the *discussion* of psychosocial distress of cancer patients (cf. Boyes et al., 2006; Detmar et al., 2002;

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[3] There might be a cultural element in the cut-off point. Many countries, including The Netherlands, seem to have 5 as a cut-off point (Bulli et al., 2009). However, Clover et al. (2016) report a cut-off point of 4 as “widely validated” (p. 4450), and Bulli et al. (2009) report a cut-off point of 7 for cancer patients in Florence, Italy.

Greenhalgh et al., 2005; Kotronoulas et al., 2014; Van Nuenen et al., 2017, Van Nuenen et al., 2018, Van Nuenen et al., 2019; Velikova et al., 2004). In The Netherlands, the IKNL aims to make sure with the use of the DT+PL that cancer survivors are systematically monitored for distress so that it is signalled and cared for in time to prevent problems from becoming more serious, and to make sure patients have a better quality of life (Integraal Kankercentrum Nederland, 2010). The guidelines developed by IKNL state that the DT+PL can be seen as a tool that helps to "discuss the problems with the patient, to assess whether the patient feels the need for extra care in any area and who is best qualified to provide this care" (Integraal Kankercentrum Nederland, 2010, p. 8, *author's translation*). The DT+PL is meant to help caregivers and patients to discuss the patient's needs – which may in itself be the first step in relieving the distress – and to refer to appropriate further care if necessary (Integraal Kankercentrum Nederland, 2010). More specifically, caregivers in follow-up cancer consultations are asked to use the DT+PL for:

1. measuring the distress levels and localising the distress areas of the patient;
2. using the findings of the DT+PL as a base for discussion with the patient, to
    a. determine to what extent the patient is able to cope with the problems by him/herself,
    b. determine whether and for which problems (more) help is required,
    c. determine how the patient can best be helped (e.g., by instant basic psychosocial care during the consultation; referral to self-help programmes or specialist care),
    d. provide basic/instant psychosocial care in the form of discussion;
3. keeping track of the development of distress in the follow-up trajectory (Integraal Kankercentrum Nederland, 2010).

1.3 Effects of instruments screening for Quality of Life

The effects on patients' wellbeing of the use of screening instruments like the DT+PL have been widely investigated in quantitative studies, but the results seem inconclusive (see e.g., Girgis et al., 2018; Kotronoulas et al., 2014; Mitchell, 2013; Palmer et al., 2011, Van Nuenen et al., 2020). As Girgis et al. (2018) state, screening with such tools "has become widely adopted, despite limited evidence that usage improves patient outcomes" (p. 88). On the one hand, some positive results have been reported. Detmar et al., (2002) found that using such an assessment of health-related quality-of-life (HRQL) as a discussion prompt "can heighten physicians' awareness of their patients' HRQL", and resulted in psychosocial issues being discussed "significantly more frequently" during the consultation (p. 3027). Velikova et al. (2004) also found an increase in the discussion of chronic non-specific symptoms, and found "benefits for some patients, who had better HRQL and emotional functioning" (p. 714). However, the findings from other studies seem to be less straightforwardly positive. In contrast to Velikova et al. (2004), Boyes et al. (2006), in their study of whether doctors' awareness of patients' psychosocial distress affects patients' wellbeing, conclude that "[r]eductions in levels of anxiety, depression and perceived needs among intervention patients were not significantly different to control patients" (p. 163). Hollingworth et al. (2013) conducted a randomised controlled trial of patients receiving usual care versus patients using the DT+PL for needs assessment and found no effect of the use of the DT+PL on psychological distress or quality of life. On the basis of a systematic literature review into the effect of the use of patient-related outcome measures (PROMs) like the DT+PL, Kotronoulas et al. (2014) concluded that "the number of statistically significant findings were limited and PROMs' intervention effect sizes [on health service outcomes] were predominantly small-to-moderate" (p. 1480). An intervention study in a Dutch university hospital investigating the effects on HRQL of head-and-neck cancer outpatients who received nurse-led delivery of the DT+PL, accompanied by nursing aftercare showed that although the patients were positive about being able to discuss their problems with the nurses, "the DT&PL+intervention did not reduce depressive symptoms or worry of cancer recurrence, or improve HRQL" (Van der Meulen et al., 2018, p. E28).

2.0 Theoretical perspectives

As detailed above, a large body of research on the DT+PL using a quantitative approach has already been conducted. Since this research has yielded inconclusive and sometimes contradictory results, the current thesis adds a new perspective by analysing the use of the DT+PL through a *qualitative* approach, which is a recommended approach for use when "quantitative measures cannot adequately describe or interpret a situation" (Hoepfl, 1997, p. 49). Qualitative research does not aim at identifying causal relationships or at generalising findings to wider populations; instead, it aims to arrive at a deeper understanding of the phenomenon under analysis (Golafshani, 2003; Hoepfl, 1997). Such research is data-driven, i.e. it starts from data rather than hypotheses and often requires a combination of methods of analysis that fit the data. It studies "things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them" (Walia, 2015, p. 2), i.e. the insider perspectives of the interactants on the communicative situation they find themselves in.

Since the current project focusses on interactional data, i.e. discourse in action, and the insider perspectives of the participants, a triangulated discourse analytical approach has been chosen, a research design developed by e.g. Sevigny ('triangulated inquiry') which "combines multiple observation perspectives with multiple data-collecting strategies, multiple data-processing, and multiple data analyses" (1981, p. 74).

2.1 Triangulation

In ethnography and other forms of qualitative research into human behaviour and interaction, triangulated inquiry (Sevigny, 1981) – also known as 'between-method triangulation' (Denzin, 1970) – is a much-used methodology. It entails studying a phenomenon through a combination of data-gathering techniques and methods of analysis (Cohen et al., 2007; Denzin, 1970; Denzin, 2012; Flick, 1992; Flick, 2007; Nøkleby, 2011; Sevigny, 1981). It assumes that each method of analysis has its strengths and weaknesses, and therefore, using a single method when analysing human interaction may yield only a restricted and perhaps biased picture of human behaviour (see e.g., Cohen et al., 2007; Denzin, 1970). Combining methods – i.e. triangulation of methods – would balance the weaknesses of one method with the strengths of another and would therefore be a means of reducing bias (Denzin, 1970; Nøkleby, 2011; Patton, 1990). Others argue that different methodologies simply create a richer and fuller picture of the phenomenon under study, enabling the researcher to report on the object of study from different angles (e.g., Flick, 2007). This also seems to be the position of Sevigny (1981), who argues that triangulated inquiry, i.e. combining observational data (gathered either through participant observation or through audio/video-recording of a communicative event) with interviews with informants (persons who have knowledge about general aspects of the event) and interviews with participants in the observed event allows researchers to supplement their own observations with the perspectives of insiders: "their motives, their intentions and their interpretation of the events in question" (p. 70).

The current study uses 'between-method triangulation' (Denzin, 1970; Denzin, 2012), with different qualitative methods of inquiry (discourse analysis, ethnography of communication, conversation analysis and linguistic pragmatics) and different types of data, gathered through observation and interviews (cf. Sevigny, 1981), which combine a focus on “the observable [...] practices of members” with their “everyday, expert or biographical knowledge” (Flick, 2007, p. 66). This combination of types of data and methods will be the means to explore different dimensions of the communicative events under investigation. As argued by Flick (2007), the most consistent way of conducting triangulated inquiry is to apply (all) the methods to the same cases, in other words to observe and interview the same persons. This has therefore been the approach in the current study: the doctors and patients who were observed and recorded in interaction were also interviewed.

2.2 Discourse analytical approaches to analysis

Discourse analysis is a broad field of inquiry with many subdisciplines, each wielding their own definitions of the field. These definitions , however, all fall into three main categories, with discourse analysis being described as concerned with “(1) anything beyond the sentence, (2) language use, and (3) a broader range of social practice that includes non-linguistic and nonspecific instances of language” (Schiffrin et al., 2001, p. 1). Medical discourse analysis focusses on how doctors and patients construct the “sequential, situated discourse” (Ainsworth-Vaughn, 2001, p. 453) of the medical encounter, with the ‘praxis’-oriented strand of the field focussing on whether certain types of talk have a positive influence on health, and the more ‘discourse’-oriented strand focussing more on “who will speak, about what, and when” (Ainsworth-Vaughn, 2001, p. 454). The current project will straddle these two types: it will focus on stretches of talk-in-use (doctor-patient communication) in a specific social practice (the follow-up head-and-neck cancer consultation) to gauge the effects of a discussion tool (the DT+PL) on the construction of the discussion of psychosocial distress.

As Lakoff (2001) argues, discourse analysis is by definition multidisciplinary; it includes a variety of ways in which researchers conduct the analysis of language use in interaction, ranging from linguistic pragmatics and conversation analysis to ethnography of communication, syntax and sociolinguistics. Studies on medical discourse have been conducted in many of these disciplines and yielded valuable insights into a wide range of topics, including, for instance, the medical encounter as a genre (see e.g., Ten Have, 1989); the ways doctors structure their consultations (e.g., Robinson, 1998; 2001; 2003; 2006); and how cancer fears are discussed (e.g., Beach et al., 2005). The current study will triangulate insights from ethnography of communication, conversation analysis, and linguistic politeness theory, all of which have as their object of inquiry language in use, i.e. language as it occurs naturally, in real-life situations.

Ethnography of communication

As Baxter (2010) states "[t]he hallmark of discourse analysis is its recognition of the […] context dependence of participants' discourse" (p. 124), i.e. the recognition of how participants' construction of discourse varies depending on the situation in which they find themselves. As early as 1923, Malinowski showed that an utterance can only be understood "when we interpret it by its context of situation" (1923/1946, p. 310), and that in any given situation, the structure of each utterance is dependent upon "the momentary situation in which it is spoken" (p. 312).

Ethnography of communication was designed to help surface the implicit cultural rules that participants orient towards in any interaction, i.e. what people (need to) know about a situation to be able to communicate appropriately ('communicative competence'; Hymes, 1972b). It focusses on how participants orient towards context, and aims to show how interactants in various communicative contexts orient to norms of behaviour that are appropriate to that context and that are taken for granted by the participant; i.e. it shows the abilities of participants to "judge appropriateness between sign (or message) and context" (Hymes, 1964: 40); to determine whether any speech act of a participant in the encounter is 'appropriate' and 'acceptable' in that particular context. The basic unit of analysis is the 'speech events', i.e. "activities, or aspects of activities, that are directly governed by rules or norms for the use of speech" (Hymes, 1972a: 56), or more broadly "the rule-governed activities of everyday life" (Garfinkel, 1964: 225). Speech events include, for instance, funerals, maths lessons, trials, and medical consultations.

For medical interaction, the importance of context was argued e.g., by Helman (1984), who states that before we are able to 'decode' doctor-patient communication, we need to examine the context in which this communication takes place, both in terms of internal contexts (e.g., the experiences and preconceptions of both doctors and patients) and external contexts (the setting in which the interactions take place). In response to different settings, contexts and prompts, participants may construct the consultation differently, may construct the relevance of topics differently, or foreground different problems (cf. Nøkleby, 2011). What people say and do, how they interpret what is said and done – and therefore the *analysis* of what participants in a particular event say and do – is dependent on the context. It is therefore important that we understand the context of the interaction under analysis, in the current case the context of doctor-patient interaction during the follow-up head-and-neck cancer consultation.

Since the DT+PL will be introduced as an extra element in the medical consultation, and will thus change the context of the medical interaction, the introduction of the DT+PL is hypothesised to have an effect on the interaction of the participants because participants will orient to the new context. To enable a comparison between interactions in the 'old' context (without the use of the DT+PL) and the 'new' context (with the use of the DT+PL), the first step in the current study will therefore be the creation of a benchmark, an analysis of the contextual parameters of the standard follow-up head-and-neck cancer consultation as a speech event (see Chapter 2).

Conversation analysis

Within the discipline of ethnomethodology, conversation analysis (CA) emerged (Ten Have, 1995), an approach to the study of interaction initially developed by Sacks, Schegloff and Jefferson (Schegloff, 1968; Schegloff & Sacks, 1984/1973; Sacks et al., 1974; Schegloff, 2007). They posit that – in the same way that interactants orient to norms of *behaviour* in social contexts – interactants "at all times whatever the setting" orient to *discursive* norms, i.e. to an orderly "interactional infrastructure" (Hall, 2019, p. 82). CA research has surfaced a series of elements of this discursive infrastructure, including the construction, distribution and allocation of 'turns at talk'; the 'sequence organisation' of talk – i.e. how in adjacency pairs such as question-response the first action (question) projects a next action (response), which "can be seen to be officially absent" if it does not appear (Schegloff, 1968, p. 1083); and 'preference organisation', which shows that structurally 'preferred' actions (such as the acceptance of an invitation) require less interactional work than structurally 'dispreferred' actions (such as the declining of an invitation), which are typically accompanied by excuses, delay, etc. (Pomerantz, 1984).

To surface this interactional infrastructure, CA uses as data audio- or video-recordings of real-world interactions which are transcribed in great detail, taking into account hesitation markers, prosody, gaze, etc. These data are then subjected to an utterance-by-utterance analysis of how the interaction is discursively co-constructed by the participants, leading to a description of the sequential structure of the interaction as it is built up by the interactants.

CA maintains that interaction is context-shaped and context-renewing. Maynard & Heritage (2005) describe this with an example from medical interaction: "The production and understanding of an utterance as an action derives from *features of the social context*, most especially an utterance's place in an organised sequence of talk. [...] Firstly, the action is *context-shaped*. [...] A terse diagnostic pronouncement can be heard as such by virtue of its placement in the physical examination portion of the encounter. Secondly, conversational actions are *context-renewing*. [...] When a diagnosis has been pronounced and received, it occasions the relevance of a treatment proposal. In this sense, the context of a next action is inevitably renewed with each current action" (429-430).

CA has been widely used to analyse medical data and has yielded a wealth of information about medical interaction (see e.g., Barnes, 2019; Heritage & Maynard, 2006a; Koole et al., 2017; Robinson, 2013; Rogers & Todd, 2010; Stommel et al., 2019). It has uncovered the wide range of discursive strategies which doctors and patients use to accomplish their interactional goals, for instance, the ways in which patients construct the reason for their visit, and the doctorability of their complaints (Heritage & Robinson, 2006a); and the ways in which doctors deliver and patients respond to diagnostic statements (Peräkylä, 1997). It has shown how doctors and patients construct different interpretations as to whether 'stable cancer' is good news (Beach, 2020), and how patients' 'appropriate' timing of asking questions (see e.g., Frankel, 1990 and Ten Have, 1993) makes them more likely to be answered by the physician (Roberts, 2000). As Heritage & Maynard (2006b) argue, analysing how the medical encounter is co-constructed by doctor and patient together "is a direct research embodiment of patient-centredness, because it includes physicians and patients both within the nexus of communication through which medicine is practiced" (p. 20; see also Peräkylä, 1997). In the current study, turn-by-turn analysis of the interaction will show how the participants co-construct and renew the medical context of the consultation, and how the DT+PL may influence this.

Linguistic pragmatics: Politeness and face

Linguistic politeness theory is concerned with people's 'public self-image', their 'face' (Brown & Levinson, 1987/1978). Brown & Levinson claim that universally, people show awareness of, respect, and protect their own face and that of their interactants. They do so by avoiding 'Face Threatening Acts' (FTAs) or redressing them through 'positive politeness', which centres around people's positive face (their need to be liked, to belong) and through 'negative politeness', which centres around people's negative face (their need for autonomy). Positive politeness strategies utilise closeness and solidarity markers, whereas negative politeness strategies utilise e.g., indirectness, hedges and hesitation, and the creation of the possibility to refuse a request or negate a possibility. The seriousness of an FTA, and therefore the need and ways to redress or mitigate it, depends on the social distance and relative power of the interactants, and the strength of the imposition.

The analysis of FTAs and politeness strategies is closely related to the notion of preference in CA. CA has demonstrated that structurally preferred responses (such as the acceptance of an invitation, agreement with an assessment) are simple and direct in structure, whereas dispreferred responses (such as refusals and disagreement) need more interactional work (Pomerantz, 1984). Where CA *describes* how dispreferred responses are preceded by e.g., hedges, delay, and pre-sequences, politeness theory *explains* how this interactional behaviour is related to the protection of face (Brown & Levinson, 1987/1978). Since doctor-patient interaction involves possibly serious FTAs (such as e.g., disagreement between doctor and patient about diagnoses or options for treatment) the combination of CA and politeness theory should be a profitable approach for analysis.

3.0 Background to the data

Since the study was instigated at the request of a team of head-and-neck oncologists who were considering the implementation of the DT+PL into the follow-up consultation, and who wanted more information on how the DT+PL would impact these consultations, this type of consultation and this group of patients will provide the data for the study. The choice for a single type of consultation (excluding e.g., visits featuring diagnosis, treatment plans, and test results) and a single group of patients allows for a focussed analysis of the data, which will facilitate the envisaged comparison between the consultations with and without the use of the DT+PL.

Follow-up is the period during which cancer patients who have finished treatment and are not experiencing a return of the malignancy (Rowland et al., 2006) are monitored at regular intervals for return of the malignancy, for after-effects of the treatment and the disease, and to relieve anxiety (Integraal Kankercentrum Nederland, 2010). The standard period of follow-up in The Netherlands is four to five years, with doctor and patient first meeting every three months, with decreasing frequency as time progresses, till once a year if all goes well.

Head-and-neck cancer survivors are an especially relevant group for research into HRQL and psychosocial distress. Depending on type of tumour and treatment, they may suffer from a wide range of extremely invasive after-effects of the malignancy and its treatment, which vary in seriousness and duration. The excision of the tumour may, for example, lead to disfigurement due to scarring in the face, the (partial) loss of an eye, an ear or the nose; to difficulties in communication through the removal of the voice box or (part of) the tongue; to lack of mucus which causes difficulties swallowing and eating; and radiation treatment may lead to thyroid problems causing continuous fatigue. This may lead to low HRQL and to high levels of psychosocial distress as is shown in Gil et al. (2012): head-and-neck outpatients "were more distressed (HADS-Total) than other groups of patients (head-and-neck cancer, 14.78; breast cancer, 8.88; colorectal cancer, 10; p = 0.05). In terms of coping scores, head-and-neck cancer patients had higher levels of anxious preoccupation than other patients (head-and-neck cancer, 23.42; breast cancer, 22.49; colorectal cancer, 19.91; p = 0.05)" (p. 364).

The main focus of this study will be on the effects of the DT+PL on the discussion of psychosocial distress in the context of the follow-up head-and-neck cancer consultation. To create as rich, complete and informative a picture of the event under analysis as possible, the current study will make use of a triangulated approach combining the following data:

- video-recordings of consultations;
- interviews with the participants (physicians, patients and companions);
- a video-recording of a training session on the use of the DT+PL;
- the patients' filled-out DT+PLs;
- the patients' medical data;
- observations (field notes) made by the researcher at a head-and-neck out-patient clinic at the hospital.

The different data will feed into each other: each set will provide a different perspective on or dimension of the consultation and the (use of the) DT+PL. The interviews with patients will give information on how they see and experience the follow-up cancer consultation, their interaction with the doctor, and the use of the DT+PL. The filled-out DT+PLs will give information on the patients' level of distress and the causes thereof. As such, they may provide insight into possible topics for discussion during the consultation. Similarly, the patients' medical data will give information on what might be relevant (medical and psychosocial) topics of discussion during the consultation. The training session will give information on the aims of the use of the DT+PL, the 'preferred' way of discussing it, and the attitude of the doctor-participants towards using the DT+PL. The video-data of the interviews with the doctors will show how the doctors see the aims of the follow-up consultation, their role, what they experience as difficult, and their perspective on the 'relevance' of (types of) topics. The video-recordings of the consultations will give information about the 'culture' of the follow-up consultation; show how doctor and patient (and companion) together construct the consultation, with and without the DT+PL; show what they nominate as topics and how they discuss them, i.e. whether and how the possible topics are discussed by the participants; what, if anything, is discussed besides; and how topics are nominated, made relevant and pursued. This combination of different types of data will enable the study to explore the context, the structure and the process of the interaction, and its meaning to the interactants (cf. Fielding & Fielding,1986).

Making use of a variety of data and a multi-method analytical approach, this thesis will discuss the following questions:

- What is a follow-up head-and-neck cancer consultation as a speech event? (Chapter 2)
  This will be analysed on the basis of a set of standard scheduled follow-up head-and-neck cancer consultations, creating the baseline from which effects might be observed.
  Two questions presented themselves when analysing the data in the standard consultations. They will be discussed in separate chapters:
    - How is the 'How are you?' question used and understood in the transition from opening to anamnesis? (Chapter 3)
    - What is the 'Key' of the consultation? An orientation towards wellness or distress? (Chapter 4)
- What are the effects of the DT+PL on the consultation?
  This will be analysed by comparing data from the standard scheduled head-and-neck consultations with data from scheduled follow-up head-and-neck cancer consultations that made use of the DT+PL. The questions that will be investigated are:
    - How does the introduction of the DT+PL affect the contextual parameters and the structure of the consultation? (Chapter 5)

  - How are psychosocial problems discussed, both in a context without the use of the DT+PL and with the use of the DT+PL? (Chapter 6)
  - How are emotional problems discussed, both in a context without the use of the DT+PL and with the use of the DT+PL? (Chapter 7)

Two points to note:

1. As detailed above, the current study is designed as a multidisciplinary study in the field of discourse analysis in the broadest sense, aiming for a rich description of the phenomenon under investigation by using insights from various theoretical perspectives, and using a range of types of data. It should not be regarded as and is not intended to be a study in conversation analysis, ethnography of communication, etc.
2. Since the chapters of the thesis were mostly written as journal articles (some have already been published), there is some overlap in what they discuss.

Chapter 1: Data collection

1.0 Introduction

The data for this study were collected at the outpatient clinic of a team of head-and-neck cancer oncologists in the Netherlands Cancer Institute-Antoni van Leeuwenhoek Hospital (NKI). The study was conducted in accordance with the principles set out in the World Medical Association Declaration of Helsinki;[4] as such it was vetted by the Protocol Ethics Committee of the NKI, which exempted the study from full review because no formal approval was needed according to the Dutch 'Medical Research Involving Human Subjects Act'.[5] Nevertheless, the committee checked and approved the formulation of the invitation for participation in which the set-up of the study was explained and the letter of consent, and no objections were raised to the study. After approval had been granted, informed consent was obtained from the participating doctors and patients, and the data collection process was set in motion.[6]

This study was conducted using triangulated inquiry (Sevigny, 1981; see Chapter 1), using a combination of data and methods to create as complete a picture as possible of the phenomena under study. The data which form the basis of the study consist of:

- Primary data: Video-recordings and transcriptions of 42 follow-up cancer consultations (28 without the use of the DT+PL, 14 with the use of the DT+PL);
- Meta-data with which the primary data will be triangulated:
    - a video-recording and transcription of a training session on how to work with the DT+PL;

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[4] With this Declaration, the World Medical Association set out the ethical principles for conducting research using human subjects and data.

[5] Wet Medisch-wetenschappelijk onderzoek met mensen (WMO)

[6] The video-data of the consultations, the patient interviews and the training session were collected by Elin Derks MA, the first researcher involved in this project. She was also responsible for the protocol of the study, the information letter plus letter of consent that was sent to the patients, and the application for approval from the protocol ethics committee. Because of personal circumstances, Elin Derks decided to leave the project, after which the present researcher took over. Over a period of a number of weeks, the data were transferred and made accessible in a secure environment to the present researcher. During the transition period, the interviews with the physicians were conducted jointly by the first and the present researcher.

- video-recordings and transcriptions of the interviews with the four doctors and 42 patients involved in the study;
- the filled-out DT+PLs of the patients;
- the patients' medical data;
- and the author's observations at the hospital.

The following sections discuss how the data were collected and processed.

2.0 Primary data: Video-recordings of the consultations

To accommodate the recording sessions of the consultations, one of the examination rooms at the head-and-neck cancer outpatient clinic was equipped with a small camera (see circle in Figure 1) and microphone.

Figure 1
Examination room with camera among equipment

Since the camera was unobtrusively placed, amidst an array of medical machinery (see circle in Figure 2), it was not immediately noticeable, nor was it in the participants' way.

The camera was placed in such a way that it captured the upper bodies and faces of the doctor, the patient and (where present) the patient's companion, sitting at either side of the doctor's desk. The camera did not have a view of the examination chair at the back of the room, so only audio-data are available for the physical examinations.

Figure 2
Position of camera

A microphone was hung from the ceiling over the doctor's desk. It was unobtrusively placed, so high that it was out of the line of vision of doctor and patient, but close enough to record sound clearly. The position of the equipment remained the same throughout the recording sessions.

Four physicians of the head-and-neck oncology team of the NKI participated in this study, three oncological surgeons and one radiation oncologist, all experienced physicians, specialised in the treatment of head-and-neck cancer. The physicians normally have between two and four regular consultation sessions per week (each lasting 3.5 to 4 hours, with timeslots for consultations of 10 or 15 minutes). The set-up of the study was designed to interfere as little as possible with the physicians' normal routine, so the recording of their consultations was planned in accordance with their regular schedule. Once the dates had been set for the recording sessions, the patients that were on the schedule were approached for participation. Between one and two weeks before their scheduled appointment, each patient was sent a letter explaining the general aims of the study and asking permission for recording, plus a letter of consent. Patients were asked to sign the letter of consent and bring it to their appointment if they agreed to participate. Before patients went into the doctor's office on the recording day, they were met by a research assistant who checked whether they had learned about and understood what the project entailed and whether they had agreed in writing to participate in the study. If patients who wanted to participate had forgotten to sign and/or bring the letter of consent, they were asked to fill out and sign a copy before they entered the consultation room.

The video-recording of the consultations was conducted in two stages. During stage one a baseline of standard follow-up consultations was collected, consisting of consultations that proceeded routinely, i.e. according to the doctors' 'normal' procedures. A selection of the video-recordings of the standard consultations forms the 'Control group' of the study (for selection criteria, see below). During stage two the data for the intervention study were collected, consisting of consultations during which a discussion tool, the DT+PL, was used to facilitate the discussion of psychosocial distress (see Introduction). The video-data of this part of the study will be referred to as the 'DT+PL group'. Two of the physicians from the baseline study, both oncological surgeons, participated in the intervention study, the DT+PL study. The other two physicians who participated in the baseline study did not continue with the project due to personal circumstances.

For the collection of the standard follow-up consultations, eight consultation sessions with four physicians – so two consultation sessions per physician – were video-recorded over a period of six weeks in March - April 2013. A total of 67 consultations with 67 different patients were eventually collected. For the DT+PL study, over a period of eight weeks in February - April 2014, four consultation sessions were recorded, two for each participating physician, in which the DT+PL was used (see below). This resulted in 20 recorded consultations with 20 different patients.

2.1 Selection of primary data

Of the 67 standard consultations, 21 recordings could not be used because patients withdrew their consent (6), the recordings suffered from technical problems (10), the consultations were hampered by language problems (3), or the participants were discussing Quality-of-Life questionnaires unrelated to the current study (2). This left 46 usable recordings. These were viewed to select the recordings that fit the focus of the current study, which compares doctor-patient communication in consultations with and without the use of the DT+PL, with a focus on routine follow-up cancer consultations. Therefore, the patients had to have finished treatment for a malignancy, and they had to have come in for their routine, scheduled follow-up cancer consultation. These selection criteria meant that a further 18 consultations were excluded from analysis, because they did not fit the routine follow-up profile: the patients were not in the post-treatment phase (1), had benign or pre-cancerous conditions (3), or came in to discuss test results (14). This left a total of 28 routine follow-up consultations for analysis. Of the 28 patients in the Control group, 18 (64%) were men, and 10 (36%) were women.

	Men	Women	Total
Dr A	5	4	9
Dr B	6	1	7
Dr C	2	4	6
Dr D	5	1	6
Total	18	10	28

Table 1 Men and women in Control group

Of the 20 DT+PL recordings in the intervention group, one did not fill out the DT+PL, and five did not match the routine follow-up profile: test results (3), benign (2), and foreign language issues (1). This left 13 usable DT+PL data for analysis. Of those 13 patients, 7 (54%) were men and 6 (46%) were women.

	Men	Women	Total
Dr A	4	4	8
Dr D	3	2	5
Total	7	6	13

Table 2 Men and women in DT+PL group

Even with these selection criteria, the participating patients were very heterogeneous: they varied in type of malignancy (varying from a melanoma of the skull to a carcinoma in e.g., the supraglottis, the nasopharynx, an ear or the base of the tongue), type and combination of treatment (excision, chemo, radiation and combinations thereof), and time passed since treatment (from a few weeks to almost five years).

2.2 Transcription of the consultations

Spoken interaction is volatile, as Haberland (2012) states: “it happens and then it is gone” (p. 3). To ensure continued access to the data, the interactions in this study have been video-taped, allowing the researcher to view the recorded interactions multiple times (cf. Ten Have, 2002). However, to be able to analyse the data, they need to be ‘entextualised’ (transcribed, turned into a text), so the data can be easily accessed, reviewed, coded, compared, and shared.

Apart from being extremely time-consuming, it is virtually impossible to transcribe an interaction completely, i.e. to render into text every utterance, every vocalisation, every gesture, every shift in posture or gaze. During every second of interaction, the transcriber needs to make choices, selecting what is transferred into text, what is left out, and deciding how to transcribe it (cf.

Bucholtz, 2007; Haberland, 2012; Roberts, 1997). At the same time, the transcription has to remain readable and interpretable. So the transcriber is involved in a balancing act between optimal accuracy and completeness on the one hand, and readability on the other (Haberland, 2012; Nikander, 2008; Roberts, 1997; Ten Have, 2002). No matter how hard one tries, the resulting transcripts "cannot be claimed to correspond exactly to the speech upon which they are based" (Bucholtz, 1995, p. 121). Nevertheless, transcriptions are currently the best modality qualitative researchers of spoken interaction have to make their data transparent and accessible in publications, short of sharing the original recordings online, which would be ethically unacceptable since it would violate the privacy of the recorded participants.

A pragmatic solution is therefore needed to the problem of transcription. Ten Have (2002) states that for some functions a 'full' transcript is needed (to build a data archive and to make particular phenomena visible), while in other publications such a level of detail may not always be necessary, since these will not focus on every phenomenon in the transcript. Bucholtz (2007) agrees with Ten Have that "sometimes a simplified transcript can make a point more concisely and clearly" (p. 788), and argues that the decision of whether or not to simplify the transcription should depend on the focus of the research, with studies in discourse *content* requiring less detail than studies in discourse *structure*. These reflections have led me to decide strategically on the level of detail, depending on the use to which each transcript is put (see below).

The data for this study were transcribed in two stages. A first-draft transcription of the video-tapes of the consultations was made by a number of research assistants.[7] Later the transcriptions were elaborated in (much greater) detail by the author, including relevant elements of body language and prosodic elements, taking into account the reflections detailed above. In the transcription, a number of considerations have been used as guidelines. As Ten Have (2002) states "the inevitable reduction, simplification and idealisation which are the effect of [the processes of recording and transcription] have to be considered in terms of the specific analytic interests that are brought to bear on the original" (p. 25). In the current study the analysis of how the participants co-constructed the interaction was one of the prime objectives. Therefore, during the entextualisation of the video-data of the consultations, the transcriptions were made as detailed as possible, with a focus on interactional

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[7] For this I give thanks to Aïsha Daw, Maja Keizers, Myriam Mulder, Silke Neimeijer, and Mara van der Ploeg.

structure. To illustrate, with respect to the transcription for nonverbal/nonvocal elements of the data, a description of gaze, nods, body alignment, etc. was given to show, for instance, how doctor and patient used this to co-construct the transition from one topic to the next, or how a patient invited a companion to take the floor. This is in line with the way CA defines 'conduct-in-interaction'; it "includes vocal and nonvocal behaviour, the use of artefacts, and any other feature of context that participants can be shown to orient to (vocally or nonvocally), including identities, roles, and relationships" (Robinson, 2007, p. 66).

When determining the level of detail of a transcription, issues of phonological detail should also be considered. In many types of studies, phonological details of the dialect of the interactants may be relevant to transcribe, for instance in critical discourse analysis studies focussing e.g., on how differences in social position between doctor and patient affect the power relations in the interaction, or in studies in the field of variationist sociolinguistics, focussing e.g., on register variation in formal and informal parts of the consultation. However, such issues are not the focus of the current study, and besides, the transcription of phonological variation might inadvertently lead to the stigmatisation of some of the participants (Bucholtz, 2000; Preston, 1985; Roberts, 1997). Therefore, I have chosen to render the verbal exchanges in the consultations as 'words-as-uttered' rather than 'sounds-as-uttered' (Ten Have, 2002), transcribing the interaction in standard Dutch orthography without representing the social and regional varieties of Dutch that occur in the data. This also sidesteps the problem of accurately rendering dialects without the use of the International Phonetic Alphabet, which can only be deciphered by people with knowledge of this orthographic system (cf. Ten Have, 2007), or using eye-dialect or 'respelling' (e.g., 'haftuh' for 'have to'), which has a tendency to be inconsistent and idiosyncratic and therefore difficult to decipher (Preston, 1985; Roberts, 1997), often forcing the reader to read the text out loud in order to understand what is on the page. Informal contractions and elisions have been included in the transcripts to indicate the tone of the interaction.

The transcription system used in this study is a commonly used, somewhat simplified version of the transcription system developed for CA by Gail Jefferson (see e.g., Jefferson, 2004; see Appendix 2). It allows for the systematic notation of e.g., overlap, pauses and emphasis, to give the reader and the analysts as complete an idea as possible of how the utterances were vocalised. As such it is able to "evoke those aspects of the hearable sounds that have in the

CA tradition acquired a status of potential interactional relevance" (Ten Have, 2002, p.41).

In this thesis I have tried to create as full, accurate and complete a set of transcriptions of the data as I can. Still, I want to end this subsection with the usual *caveat* in connection with transcription, which emphatically remains in force: no matter how detailed and accurate the transcriptions end up as being, a transcript remains an artefact, based on a recording of the live interaction. Both readers and analysts need to bear in mind that it is only a partial representation of the interaction and cannot take the place of the actual recorded data (Haberland, 2012; Ten Have, 2007).

2.3 Translation

In many international publications with strict word limits, qualitative researchers reporting on non-English data are forced to limit themselves to presenting the English translations of their data rather than the original transcripts, or to 'hide' the original data in the appendix (Nikander, 2008). This makes the data difficult to access, and so difficult for the reader to interact with, which is an undesirable situation (cf. Ten Have, 2007). The format of a PhD thesis makes it possible to show both the original transcript and the English translation. The video-data of the current study have been entextualised in the original Dutch and are presented in the text of this study in Dutch, accompanied by an English translation to allow readers who are unfamiliar with Dutch access to the data.

There are some inherent problems to presenting data in translation. Translation may lead to confusion on a number of fronts. There is the possibility of confusion on the linguistic front: languages differ in how they formulate concepts, in how they divide up the world, and in the connotations associated with terms and phrases. A translation needs to navigate all of these issues. Besides this, the context in which the words and phrases are uttered is also different, which may lead to confusion if not explained (cf. Pösö, 2014): things are not just *said* differently in different countries; the institutional *setting* in which they are said may also differ. For instance, as argued by Ten Have, medical consultations are both structured events "with an established progression of 'slots' to be filled by the participants" (1995, p. 253; see Chapter 2), and 'interactional streams' (e.g. question-answer sequences, information-and-acknowledgement sequences) which are interactionally negotiated between doctor and patient. These slots and streams may be culture-specific, and this may result in things being *done* differently in different cultures, with people from different cultures having different frames[8] which inform them (Minsky, 1974) and which they orient to when they co-construct an interaction. As formulated by Temple and Young, "Your location within the social world influences the way you see it" (2004, p. 164), and thus your own cultural background may 'warp' your interpretation of interaction in a different culture/language. Doctors and patients in the UK or the US may construct consultations differently from doctors and patients in The Netherlands (cf. Temple & Young, 2004).[9] Translation may hide some of these differences, in that Dutch cultural knowledge is translated into English words and phrases, which to the English-language reader may evoke frames of reference that are different from the Dutch context to which it is supposed to refer. Pösö (2014) argues that, to avoid such problems, researchers should use translations that "make visible rather than hide the transformation of knowledge which has taken place in inter-language communication" (p. 623-624; cf. Temple & Young, 2004). This has led me[10] to not always search for the most idiomatic translations, but – where necessary – to search for more literal (but still understandable) translations which prevent the 'strange' from sounding 'familiar', to "allow for differences in understandings of words, concepts and worldviews across languages" (Temple & Young, 2004, p. 171). It is hoped that this will prevent readers from linking the original Dutch utterances to 'unwarranted' connotations in the English translation. Nevertheless, the translation is as close and as idiomatic as I was able to manage. Special care has been taken to maintain the location of or give equivalent positions for turn boundaries, overlap, pauses and hedges.

There are various formats in which a translation can be presented, e.g. in blocks of text following each other, line by line (alternating the original with the translation), or in three-line format, with the first line representing the original,

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[8] Defined by Minsky (1974) as "a data structure for representing stereotyped knowledge". The information in such a frame includes "what one can expect to happen next", so the Act sequence of a communicative situation.

[9] So, in order to understand interaction conducted in different country, in a different language, it is necessary to understand the cultural and institutional context in which the interaction is conducted. See Chapter 2 for a description of the Dutch follow-up head-and-neck cancer consultation.

[10] Being fluent in both Dutch and English, and an experienced translator, I have not had to depend on outside translators to translate the data for me. However, I have conferred with two of my colleagues at the Department of English Language and Culture (Hannah Kousbroek and Imogen Cohen) – both bilingual English Dutch, and both experienced professional translators – to help me find solutions for difficult translation points. Any remaining errors are mine alone.

the second line representing the grammar and conjugations of the original, and the third line giving a free translation (see Example 1.1 for a simplified 3-line translation). Such three-line transcriptions take up a lot of space and are cumbersome to read, so it makes sense to only use them if it is absolutely necessary.

Example 1
Three-line translation

```
Dr:   Hoe gaat het met  u            (.) intussen?
      How goes it  with you [FORMAL] (.) in the meantime?
      How have you been (.) in the meantime?
P:    Gaat goed denk  ik
      Goes well think I
      Doing OK I think
```

Ten Have (2007) states that three-line transcriptions are especially suitable for languages that differ greatly from one another, while languages that resemble each other more closely, such as Dutch and English, can be translated almost word-for-word, and do not need such an 'in-between' line. Since the current study works with two closely related languages (Dutch with a translation into English), a three-line translation is deemed unnecessary. In the interest of readability, I have opted for a parallel translation/transcription format, presenting the translation in the left-hand column and the original Dutch in the right-hand column. Since we read from left to right in Germanic languages, this ordering foregrounds the translation rather than the original (Nikander, 2008). However, since the thesis is written in English, this order makes it easier for the reader to process the data.

The analysis of the data was conducted on the basis of the video-tapes and the original transcripts, so on the basis of the original Dutch interaction. The tapes and the Dutch transcripts form the main body of the data, showing how doctor and patient co-construct the interaction based on their interpretation of the speech event that they are involved in. In the discussion of the data I will refer to the English translation for ease of reading.

3.0 Meta-data: Interviews and training session

Video-recordings were made of the interviews with the patients, the interviews with the doctors and the training session on how to use the DT+PL.

3.1 Interviews with the patients

At the end of each consultation, the doctors asked the patient (and their companion) to go to the next room for an interview with the first researcher. While the doctor conducted the next consultation with the next patient, the first researcher conducted an open-ended free-form interview with the patient of the preceding consultation and their companion, if present. These interviews were video-recorded.

At the start of the interview, the interviewer first introduced herself, established the identity of the participants (patient and – where relevant – companion), re-confirmed permission and re-established that patients could withdraw from the project whenever they wished. Interviewer then recorded the date, time and physician for the tape. The patients were asked how they had experienced the consultation and the interaction with the physician; whether they had been able to discuss everything they wanted; and what – if anything – stood out especially about this consultation. At the end of the interview, patients were also asked to rate the physician on a scale of ten, and to motivate their assessment. Patients in the DT+PL group were asked some extra questions: how they experienced the filling out of the DT+PL and how they experienced discussing it with the physician. In both sets of interviews, whatever the patients nominated as topic was considered relevant and followed up with continuers and questions.

3.2 Interviews with the doctors

After the collection of the video-data of the consultations had been completed, the author together with the first researcher conducted interviews with the four physicians who participated in the study. These interviews were video-recorded. The interviews included questions on the views of the physicians on (how to conduct) the follow-up consultation; its aims and their role in it; what made the consultations difficult; and when they were satisfied or dissatisfied with a consultation. As with the patient-interviews, whatever the doctors nominated was considered relevant and followed up.

3.3 Training session

The two physicians who participated in the DT+PL study had never worked with the DT+PL before, so to initiate them into its aims and use, they received a one-hour training session conducted by an experienced oncological nurse, well-versed in the use of the DT+PL. The first researcher was present during the training session and made a video-recording of it. During this session practical issues of how to work with the DT+PL were discussed, as well as any issues and questions the physicians had relative to the DT+PL. Important elements in the training included what the cut-off point is for problematic distress, and what would be the preferred procedure with patients whose DT+PL scores were problematic. The participants also discussed any worries and issues related to the introduction of the DT+PL in the follow-up head-and-neck cancer consultation.

3.4 Transcription of the interviews and training session

As noted above, Bucholtz (2007) argues that researchers may make radically different transcripts of data depending on whether the focus is mainly on discourse *content* or discourse *structure*. The research focus of the interviews and the training session is only on discourse content, to triangulate participants' perspectives with the interactional data from the consultations. Hence, the video-tapes of the interviews and the training session were transcribed 'verbatim', word-for-word, without the level of detail regarding how the utterances were rendered (e.g., hesitation, pauses, prosody) that was used in the transcription of the video-tapes of the consultations.

4.0 Meta-data: DT+PLs

All the patients filled out the DT+PL (see Introduction for a discussion of its elements). When the patients participating in the intervention study, the DT+PL group, arrived at the clinic, the research assistant asked them to fill out the DT+PL in the waiting room. As background information they were told variations of 'This is a list of frequent complaints of cancer patients. We would like to know whether you recognise one or more of these complaints for yourself'. The patients were asked to take the filled-out DT+PL with them into the consultation room and hand it to the physician. The physician had been instructed to integrate the DT+PL into the consultation. When the consultation was finished, the patients took the DT+PL with them to the interview room, where they handed it to the first researcher at the start of the interview (see section 3.1).

Patients participating in the Control group received and filled out the DT+PL after the post-consultation interview and were given similar instructions as the DT+PL group. They handed the filled-out DT+PL to the staff at the desk of the clinic. This ensured that neither doctor, nor patient, nor interviewer knew what was in the DT+PL during the consultation and interview.

5.0 Meta-data: Medical records

From the patients' medical files, the data on diagnosis of the head-and-neck malignancy, type of treatment and time since last treatment were gathered. This enabled the author to select only those patients who were in follow-up and to exclude patients with benign conditions.

6.0 Meta-data: Personal observation

The author was present as an observer at a follow-up head-and-neck cancer clinic in April 2015, observing Dr E (a colleague of Doctors A, B, C and D) conducting a clinic. She made notes during the clinic and asked questions afterwards. She was also present at meetings, discussions and informal gatherings of doctors, nurses, researchers and speech therapists over a period of three years. These observations informed her description and analysis of the data.

Chapter 2: The follow-up head-and-neck cancer consultation as a speech event

1.0 Introduction

Drew & Heritage's (1992) analysis of institutional environments like education and medicine shows that interactions in these settings tend to exhibit a number of specific characteristics: they involve specific goal orientations, i.e. an orientation to specific tasks; there are role-structured institutionalised asymmetries between participants, with different distribution of knowledge, resources, etc.; these goals and roles lead to constraints – implicitly agreed on by the participants – on allowable contributions to the discussions of the business at hand (e.g., who can speak, what can each speaker contribute); and there are specific inferential frameworks in place, where certain behaviours – e.g., absence of affiliative response – which would be out of place in ordinary interaction, are interpreted as appropriate and serving a specific function. For the analyst, therefore, the study of the characteristics of the institutional context might be a helpful first step to understanding the interaction in the institution.

A notion that has been used extensively to analyse the characteristics of institutional contexts and institutional discourse is the 'speech event', an analytical concept anchored in the 'ethnography of communication', advocated by Hymes (1977). Ethnography of communication employs a qualitative methodology, aimed at gaining insight into the meaning of people's behaviour through an understanding of the 'emic' or participant perspective, so through an understanding of the participants' "predispositions, purposes, assumptions, values, expectations, and attitudes" (Sevigny, 1981, p. 66). It endeavours "to capture what people *say* and *do* as a product of how they interpret the complexity of their world" (Sevigny, 1981, p. 68), i.e. to capture how what people say and do is constructed on the basis of the insider relevance, and insider expertise of the participants. This 'communicative competence' is rooted in people's knowledge of (and becomes apparent to the researcher by observing how they orient to) the cultural rules that govern "when to speak, when not, […] what to talk about with whom, where, when and in what manner"(Hymes, 1972b, p. 277), which are specific for each type of speech event.

Hymes (1972a) defines the speech event as follows: “The term speech event shall be restricted to activities, or aspects of activities, that are directly governed by rules or norms for the use of speech” (p. 56). Examples of speech events include business meetings, court cases, university lectures, and religious ceremonies, i.e., clearly recognisable communicative activities, with a specific aim (e.g., to reach agreement on a business plan or to teach a subject to a classroom full of pupils), and a specific set of expectations as to how the participants will conduct the event. Participants share understanding of what is going on throughout the event, in the sense that they share understanding of the purpose, and the social and communicative rules of the event. If speech events derail, if the rules are broken, lack of shared understanding of what is going on may be the result. As such, the notion of speech event is related to ‘schemas’ and ‘frames’, “structures of expectation” (Tannen & Wallet, 1987, p. 205) about ways of behaving in specific social situations.

To aid the analyst in determining what knowledge of the context participants orient towards in a specific speech event, various heuristic tools have been developed, particularly by scholars focussing on theories of meaning. Firth, for instance, divided “a typical context of situation” into relevant features of the participants, verbal and non-verbal action, the objects in the situation, plus the effect of what is said in the situation (Robins, 1971, p. 37). Halliday (1994) similarly employed ‘field’ (the action), ‘tenor’ (the participants) and ‘mode’ (the channel and the role of language). Hymes (1977), not so much focussed on language *meaning*, but rather on the language *use* of competent participants in a speech event, devised the more elaborate SPEAKING model, further developed by Saville-Troike (2003). The name of the model is an acronym, referring to, respectively, the ‘Setting’ of the speech event, the ‘Participants’ and their roles, the ‘Ends’ or aims, the ‘Act sequence’ of the event (similar to ‘move structure’; Swales, 1990), its ‘Key’ or mood, the ‘Instrumentalities’, the ‘Norms’ governing the interaction and the ‘Genre’.

The SPEAKING model is formulated in terms of what the participants of the interaction themselves orient towards as relevant in the speech event, i.e., the “knowledge that speakers must possess to successfully manage a given speech activity” (Langlotz, 2015, p. 522). This entails that not every element of the model may be equally relevant to the participants in different speech events. Also, since a speech event is an organic whole, each of the elements is related to, influences and is influenced by the other elements. For instance, the different Ends may influence the way the interaction is organised, the orientation of the participants, their designated speaker roles, and the ways in which they co-construct the interaction (cf. Swales, 1990).

One of the functions the SPEAKING model is intended to perform is to enable comparisons between communities; it provides "a set of categories for the discovery of similarities and differences" (Fitch & Philipsen, 2009, p. 122). Since comparison of two different ways of conducting the follow-up cancer consultation (with and without the use of the DT+PL) is the aim of the present study, the current chapter will make use of this model to analyse the complex institutional context of doctor-patient interaction in follow-up cancer consultations in The Netherlands. It will analyse contextual parameters that are characteristic of the follow-up cancer consultation; identify and analyse the features which differentiate it from other types of medical consultation; and discuss how these features might influence the way the discourse in these events is constructed by the participants. The resulting description of the standard follow-up head-and-neck cancer consultation will serve as a *benchmark* on the basis of which it will be possible to determine the effects (if any) of the introduction of the DT+PL on doctor-patient interaction.

2.0 An analysis of the follow-up cancer consultation as a speech event

The data used in this analysis consist of the field notes of the researcher, the interviews with doctors and patients and the observational data from the video-recordings of the standard consultations (Control group) and training sessions (see Chapter 1, Data collection).

2.1 Setting

The Setting of the follow-up cancer consultation involves the time, place and physical circumstances of the consultation (Hymes, 1977; Saville-Troike, 2003).

Time

Time-wise, the follow-up cancer consultation under investigation is embedded in a chronological string of consultations over a period of five years or more. This trajectory moves from a visit to the family doctor (GP) with a complaint, to referral to a specialist, diagnosis, and treatment. After treatment has been completed, the next series of doctor-patient encounters start, the string of follow-up cancer consultations, which are the focus of the current analysis: in The Netherlands, cancer patients typically return to the outpatient cancer clinic

– first as frequently as once every few months, later about once a year – for four or five years after treatment. The place of the follow-up cancer consultation in the chronology of the disease – starting after treatment and ending either if and when it returns or after five years when statistically recurrence is deemed to be unlikely – entails that this is a period when the patient is expected to be healthy (Rowland et al., 2006).

One of the most salient aspects of the follow-up cancer consultation is that it is a ‘return visit’. Since in the hospital in this study the physician who conducted the treatment of the patient is usually also the one conducting the follow-up, doctor and patient meet quite frequently over the years. It might therefore be argued that a high(er)-context type of interaction develops (Helman, 1984), where shared knowledge of the patient’s situation, illness, treatment and problems builds up. As Ainsworth-Vaughn remarks, patient and doctor develop “an interactional history to draw upon” (1994, p. 195). This is relevant for the type of question-and-answer sequences in anamnesis (see ‘Act sequence’ below), which will focus on how the patient has been since the last visit (see also Chapter 3).

The shared interactional history is often reflected in the language, with both lexis and deictic elements referring back to previous interactions (see e.g., Gafaranga & Britten, 2005), as shown in Data 1, where Dr C refers to the period between the current and the last visit by means of ‘in the meantime’.

Data 1
Consultation Dr C

P1	Dr: how have you been in the meantime	hoe gaat ’t met u (.)in de tussentijd
P2	Pt: quite well	behoorlijk goed

The ‘return visit’ character of the follow-up consultation also affects the level of expertise about the ‘procedural rules’ (see ‘Norms’ below) of the speech event that participants orient to. Where the medical staff are long-term bona-fide members of the discourse community of oncology experts, and unquestioned experts in the follow-up consultation speech event, the patients and their companions are – when they enter into the follow-up stage of the cancer process – mostly new to this type of medical consultation (cf. Swales, 1990). However, as their experience with the follow-up consultation grows over the years in which they are being monitored, so does their expertise in the speech event, as is witnessed, for instance, by their anticipation of possible questions by the oncologist, and their references to expected procedure (see Data 2).

Data 2
Consultation Dr B

P1	Dr:	=no complaints experienced nothing out of the ordinary↑	=geen last geen bijzonderheden meegemaakt↑
P2	Pt:	((shakes head no, considering)) not really(.) no ((looks at Cp))	((schudt nee, nadenkend)) eigenlijk niet (.) nee ((kijkt naar Cp))
P3	Dr:	[((shakes head and looks at Cp))	[((schudt hoofd en kijkt naar Cp))
P4	Cp:	[((shakes head)) no	[((schudt hoofd)) nee
P5	Pt:	[not with me voice and with eh=	[met me stem niet en met eh=
P6	Dr:	=voice is still OK ((nodding yes))	=stem blijft goed ((ja-knikkend))
P7	Pt:	yes °voice still OK°	ja °stem blijft goed°

Having responded to doctor's question 'no complaints experienced nothing out of the ordinary↑' with 'not really (.) no', patient continues with an elaboration that seems intended as the start of a list, checking off what could have gone wrong, but did not: 'not with my voice nor with eh'. Apparently, the patient is aware of the tell-tale symptoms of head-and-neck cancer, and he uses this knowledge to claim he is well, because he does not have these symptoms. It shows that patient has become an expert patient participant in the speech event of the follow-up cancer consultation: he has learned from previous visits what questions about his condition to expect.[11]

Timing

The timing of the individual consultations is strictly institutionalised, as the consultations are governed by appointments made through the department's administrative staff and ruled by a time-table: appointments of 10 to 15 minutes within a roster of the physician's scheduled consultation sessions. The

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[11] This sequence also corroborates the findings in Beach (2013) that "patients invoke and claim epistemic knowledge" to justify their wellness (p. 579).

average duration of the standard consultation for the four doctors in this study was 11:06 minutes, but there were some striking differences. The consultations of the two female doctors lasted 13:20 minutes on average; those of the two men 8:16 minutes. The longest consultation was one of Dr A's (20:23 minutes), and the shortest was one of Dr D's (4:19 minutes). Dr A varied between 08:04 and 20:23, Dr B between 08:15 and 19:25, Dr C between 05.52 and 12:21, and Dr D between 04:19 and 12:49.

Spending longer than the scheduled time on a consultation involves delay and longer waiting times for the following patients, and a longer consultation session for the physician. An awareness of these time-issues by both physician and patient creates a tension between what they ideally might wish to discuss and what is possible within the limited amount of time available for the consultation. It may, therefore, constrain topic selection in the actual interaction, and the depth to which topics are discussed. In Data 3, when asked about the desirability of devoting more time to issues of anxiety, Dr A states it would be preferable, but it is not always possible because the consultation-times are too short.

Data 3
Interview Dr A

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Dr A: I'd prefer it, but there is not always the opportunity – the
consultations are too short to go into this
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Time and timing, then, may affect doctor-patient interaction in various ways. Since the follow-up cancer consultation is a form of return visit, which recurs numerous times over a span of four or five years, a higher context type of interaction develops, where doctor and patient get to know each other, and patient and companion acquire expertise in the genre of the follow-up consultation. In addition, the time-schedule involved in the organisation of the individual consultations creates pressure, and influences what it is possible to discuss in each consultation.

Place

In the Dutch social context, the follow-up cancer consultation usually takes place in a hospital. This can be either at the oncology department of a general hospital or, as in the current study, at a specialised department (head-and-neck oncology) within a specialised cancer hospital. The hospital in the current study is located in a relatively new suburb of a large town in The Netherlands. In the hospital there are various clinics, each with their own reception and waiting area, located near the relevant consultation rooms. Patients check in at reception and wait in the waiting area until it is time for their consultation and the doctor comes to fetch them.

Physical circumstances

The standard consultation rooms that are used for follow-up consultations in this hospital (see Figure 1) are equipped with a desk and desk chair for the physician, and two chairs for the patient and a possible companion.

Figure 1

The physician sits at one side of the desk, and the patient (and their companion) at the other. On the physician's side of the desk there is a computer, which the physician uses to access the patients' digital files and enter the data yielded by the consultation. At the other side of the room there is a space with medical equipment and an examination chair which are used for the physical examination that is a standard element of the follow-up consultation (see 'Act sequence' below).[12]

The doctors wear white hospital coats and name tags, which identify them as members of the institutional medical community of the hospital (cf. Helman, 1984). All this together makes the physical setting of the follow-up consultation strictly institutional, creating and emphasising the medical business at hand.

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[12] For the purposes of this study, the room has been equipped with a camera and microphone to record the consultation (see Chapter 1).

2.2 Participants and roles

The default Participants in the follow-up consultation are the doctor and the patient. Without either there would not be a consultation. In many consultations the patient is accompanied by a member of the family or a friend (a companion).[13]

Whereas in many countries follow-up is executed by resident doctors, in The Netherlands, and more particularly in the hospital under analysis, it is the attending physicians themselves who conduct the follow-up consultations, usually the oncologist who treated the patient for their malignancy. If the patient was treated by more than one physician (e.g., both a surgeon and a radiation oncologist), the patient sees both of them in turn, in alternate follow-up consultations.[14]

The patients in the current study are all head-and-neck cancer survivors, who have completed treatment and entered the follow-up trajectory, a period of around four years in which they regularly see their physician to be monitored for cancer (see 'Ends' below). The malignancy and treatment they experienced may have a range of after-effects, which vary greatly in severity and duration. They include disfigurement through the removal of e.g., (part of) the tongue, an eye, or ear and other facial scarring; lack of mucus which leads to difficulties swallowing and eating; and removal of the voice box, which leads to communication problems. Apart from this there are long-term effects of radiation therapy, such as thyroid problems which may lead to continuous tiredness. Patients coming to the follow-up consultations may only have finished treatment one or two months before, or as long before as 48 months or more.[15]

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[13] For the effects of the presence of the companion on the participant structure (Goffman, 1979) and the norms of interaction, see 'Norms' below.

[14] Other possible participants include an observer (usually a junior doctor or colleague of the physician; not present in the current data), and people or telephones interrupting the consultation. Since they are not central to the follow-up consultation, they will be left out of this discussion of the context of the follow-up consultation and they will not be included in the data analysis.

[15] Some patients come to the clinic for a scheduled routine visit, others come for an extra emergency visit because they have questions or complaints. The focus of the current study is on routine visits.

Changing roles and relationships

Traditionally, the doctor-patient relationship has been seen as asymmetrical, since access to "medical knowledge and technology" is unequally distributed between doctor and patient, and this "necessarily implies a relationship in which one actor [*i.e., the doctor*] is more autonomous and the other [*i.e., the patient*] is more dependent" (Lazarus, 1988, p. 45; see also Parsons, 1951). As a consequence of this, until the late 1980s the idea that patients could participate in medical decision making was "an alien idea in Western medicine", because patients were seen as "too ignorant of medical matters and too anxious about their conditions to participate intelligently" (Lazarus, 1988, p. 45). The doctor-patient relationship was characterised by paternalism on the part of the physician, and passivity and obedience by the patient (Kaba & Sooriakumara, 2007). In the last few decades, the doctor-patient relationship has evolved, one influence being the Internet, which has diminished this asymmetry by creating better informed patients (Kaba & Sooriakumara, 2007). However, the epistemic asymmetry between doctor and patient in terms of medical knowledge and skills remains substantial. It is this asymmetry that still forms the basis of the roles of doctor and patient in the follow-up cancer consultation, the doctor's skill and knowledge being the reason why the patient goes to him/her to monitor their condition (see 'Ends' below).

More or less in parallel to the spread of information through the Internet came the advent of 'patient-centred care' in the 1990s, "whereby power and responsibility are shared with the patient" (Kaba & Sooriakumaran, 2007, p. 61), and in which 'shared decision making' (actively involving patients in the decision-making process) is seen as the ideal for medical decision making (see e.g., Kaba & Sooriakumaran, 2007; Mead & Bower, 2000; Stiggelbout et al., 2015).

The interaction between the sometimes-conflicting influences of asymmetrical knowledge and the orientation towards shared decision making comes to the fore in Data 4.

Data 4
Interview Dr D

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Dr D: If the patient leaves it to the doctor, I always try to give it
back to them. I tell them, "Yes, that is fine. I will just say what
the optimal treatment is. But it is up to you to decide what you want
to undergo".
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Here Dr D explains that he always attempts to involve patients in the decision-making process. Even in situations where patients want to defer to the asymmetric, specialist role of the doctor, he will not take the decision for them; he will inform patients about what medically would be the best treatment, but will leave it to the patients themselves to make the decision about what they want to undergo (cf. e.g., Landmark et al., 2015).

The role of the physician

Whereas in other types of medical consultation the basic role of the physician may be to form a diagnosis, and/or to propose, explain and help to decide treatment, the primary role of the doctor in the follow-up cancer consultation is to monitor the patient's condition, look for tumour recurrence or secondary primary tumours and guide the patient in rehabilitation. However, how doctors delimit this role, and what they subsume under 'the patient's condition' varies, and is tightly related to how they define the aims of the consultation (see 'Ends' below).

The role of the patient

The role of the patients in the follow-up consultation is twofold: to *inform* the doctor about their (perspective on their) condition and to *gather information* from the doctor about their condition (has the cancer come back or not?), about how to cope with after-effects, how to treat wounds, etc. This necessitates that patients communicate any symptoms, concerns or questions they have to the doctor, so that s/he can address patients' worries and concerns, determine whether or not further tests or treatment are in order, and give the information the patient needs. The importance of the role of the patient is illustrated by the many webinars and tips that proliferate on the Internet, aimed at helping patients prepare for their consultation with the doctor (see e.g., KWF Kankerbestrijding, 2016).

The role of the companion

In its basic composition there are only two participants in the follow-up consultation: the doctor and the patient. However, there is another regular participant in the follow-up cancer consultation: the patient's companion (usually a spouse, friend or relation). Patients are often advised to bring a companion to their consultation, for both moral and practical support (Street & Gordon, 2007; for examples, see e.g., Dokter.nl, 2017; Dokterdokter.nl, 2015; KWF Kankerbestrijding, 2016), and whereas such advice is absent from the online information leaflet of the hospital in the current study, many of the photographs in the leaflet picture patients coming to the hospital with a companion, thus naturalising their presence.

The role of the companion is much less clear than the roles of the default participants and seems to vary quite widely among consultations. In some cases, the companion does not verbally enter into the interaction at all. Their role then seems to consist of simply ‘being there’, to give tacit moral support, or to help the patient recall later what has been said. In other cases, the companion plays a significant part in the discourse: for example, in the case of head-and-neck cancer patients who have difficulty speaking, companions may speak for the patient. In other cases they elaborate on information that the patient gives, they co-construct, together with the patient, answers to doctors’ questions, they discuss how they help take care of patients, they provide information (including information that the patient is reluctant to give) or ask questions on how to take care of the patient (see Data 5), or questions that the patient seems to forget or seems reluctant to ask (for an example, see Chapter 7, Data 3; see also Beisecker et al., 1997; Ellingson, 2002; Laidsaar-Powell et al., 2013; Street & Gordon, 2007).

Data 5 illustrates how patient’s companion asks doctor for information on how to deal with patient’s wounds from a recent operation.

Data 5
Consultation Dr A

P1	Cp:	when is a (.) jet of water OK again↑ (.)	wanneer mag er weer een (.) straal water↑ (.)
P2	Dr:	>oh that is OK< (0.9)	>o dat mag wel< (0,9)
P3	Cp:	in the shower↑	onder de douche↑
P4	Dr:	°yes he can have a shower *hoor*°[16]	°ja hij mag onder de douche hoor°

The complementary roles of doctor, patient and companion lead to a type of interaction that is centred around the exchange of information, with both care-

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[16] The often untranslatable particle *hoor* has many functions. Kirsner & Deen (1990) mention, among other possibilities, *hoor* as a device to involve the hearer, and soften the impact of a remark. Both these functions are possible interpretations here.

giver and care-receiver in turn asking questions and giving information relevant to the purpose (see ‘Ends’ below) of the various stages of the consultation (see ‘Act sequence’ below).

2.3 Ends

The Ends (or aims) of the follow-up consultation expressed by the participants in this study clearly distinguish it from other types of medical visits, like the new-concern visit, aimed at diagnosing a new complaint, the bad-news visit, in which doctors inform patients of serious diagnoses, or the visit in which treatment is discussed for a malignancy that has been diagnosed (cf. Robinson, 2006 for other types of visits). The most salient Ends of the follow-up cancer consultation that can be distilled from the interviews and observation of the consultations include:

1. to monitor the patient for signs of recurrence, metastasis and second tumours

In follow-up consultations the first aim is to monitor the patient’s physical condition, i.e., to make sure that the cancer for which the patient has been treated has not recurred.[17] This is what Dr A in Data 6 refers to as ‘the oncological part’ of the conversation.

Data 6
Interview Dr A

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Dr A: to see if the patient is doing alright, if there is no tumour,
so that is the medical business at hand, the oncological part
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2. to reassure patient/relieve anxiety

The aim of checking for recurrence is closely related to the second aim of the follow-up consultation, which is to relieve patients’ anxiety. In follow-up cancer consultations “fears are potentially always there as a horizon for thoughts about the future. A major objective for the patients could therefore be assumed to be reassurance that ‘things are okay’” (Sandén et al., 2001, p. 140). For head-and-neck cancer survivors – the focus of this study – Gil et al. (2012) show that anxiety and depression in this group is especially high; after treatment they “were more distressed […] than other groups of patients […] [and] had higher

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[17] This may include the discussion of the possible need (or not) for further tests and/or imaging.

levels of anxious pre-occupation than other patients" (p. 364).[18] Fear of recurrence is a frequent cause for anxiety in this group (Ghazali et al., 2013). Having this fear taken away by the physician, then, is often seen as the main aim for the patients coming in for their follow-up consultations. This is shown in Data 7, where Dr B relates that patients come in hoping to be told that the cancer has not returned, which relieves their anxiety.

Data 7

Interview Dr B

`Dr B: some people of course have specific questions that they are worried about. And most people just want to hear that there is nothing to feel and nothing to see. And that is then the reassurance`

3. to monitor the (management of) after-effects, including quality of life

For head- and-neck cancer survivors the after-effects of the malignancy and its treatment can be quite severe: they include facial disfigurement, difficulties speaking after removal of the voice box or part of the tongue, difficulties swallowing/eating, fatigue, pain, and many more problems that may influence patients' physical and emotional wellbeing (see e.g., Murphy & Deng, 2015). One of the aims of the follow-up consultation is to monitor those after-effects, so that help can be given if needed. After-effects that have been bothering the patient for a long time and that are likely to be permanent require separate discussion.

In Data 8 Dr A states that it is important that patients realise that the treatment of head-and-neck cancer may result in permanent dysfunction, and that patients may never again be able to do things that they considered normal before they had cancer.

Data 8

Interview Dr A

`Dr A: Apart from that, it is important that the patient has quality of life […] In my view that largely correlates with understanding of the situation in which you have arrived. Unrealistic expectations, the disappointment that things are not yet going the way patients would like. To some extent this is permanent because patients are mutilated or have a dysfunction. But it also lies partly in the realisation and understanding that the treatment or that type of cancer has as a result that you are no longer able to do certain things.`

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[18] Distress levels on Hospital Anxiety and Depression Scale (HADS): HADS-Total: head-and-neck cancer, 14.78; breast cancer, 8.88; colorectal cancer, 10; $p = 0.05$. Anxious pre-occupation levels: head-and-neck cancer, 23.42; breast cancer, 22.49; colorectal cancer, 19.91; $p = 0.05$ (Gil et al., 2012: 364).

Quality of life, she states, is to a large extent related to patients' ability to accept this change. Expectation management is therefore also an important aspect of follow-up.

The discussion of psychosocial distress

The Ends communicated by the doctors in the current study broadly reflect the ideas that live in the broader discourse community of oncology professionals, which has generated an extensive literature on cancer consultations, with guidelines that reflect the consensus in the field on how the various consultations must be conducted. In these guidelines, the monitoring of psychosocial issues is definitely included in the aims of the follow-up consultation (see e.g., Hewitt et al., 2006; National Cancer Institute, 2010; Integraal Kankercentrum Nederland, 2010; Smith, 2015). However, whether the monitoring of after-effects includes the active monitoring of psychosocial problems and if so to what extent is a moot point among the doctors in the current study.

Some see themselves purely as (head-and-neck) oncologists, whose job it is to treat patients for cancer, and whose orientation is towards the biomedical.

Data 9
Interview Dr D

`I am in principle I am a head-and-neck surgeon […] so if someone is really a bit at odds with themselves then I think like eh we've got a supportive team for this, we've got a psychiatrist for this [..] and eh that tinkering with it oneself […] look, you have got to stay – what do you call it – let the cobbler stick to his last`

Dr D is very clear about this in Data 9, stating that it is the supportive team and the psychiatrist who should take care of patients who need psychosocial help, not the surgeon. He formulates this quite strongly, stating that as a head-and-neck surgeon one should 'stick to one's last', and not 'tinker' with such issues.

This view is also expressed by Dr B in Data 10, who considers herself unqualified to deal with psychosocial issues:

Data 10
Interview Dr B

`Dr B: And indeed of course you've got patients who are […] depressed, or yes … have other problems. Yes, those things I cannot solve myself, so then I have to refer them.`

Dr A, however, sees her role as less narrowly defined: she takes on the role of coach and mentor (which includes monitoring of psychosocial issues), but only in specific cases:

Data 11

Interview Dr A

Dr A: If I feel I have a good click with someone so have the feeling that I can be of use to someone, because you cannot do this with everyone […] then I would think that was fine […] I will do this once or twice and if that is not enough I would refer someone […] because of course there is not – I repeat – the time for this.

Interviewer: So in the first instance physician but also a counsellor?

Dr A: Yes certainly, yes certainly, I really think that is an oncological institution.

In cases where she has a good relationship with the patient and if she sees that she can be of use, Dr A will devote some time attempting to help patients with their psychosocial issues, but she will then refer them to a specialist. Although Dr A states that being a counsellor is part of the role of an oncologist, she also implies that such counselling is not structurally part of the standard follow-up consultation, because there simply is not enough time for this.

Dr A also makes clear that at the basis of the question whether or not psychosocial issues are part of the doctors' brief in follow-up lies the question of whether the psychosocial problems of the patients are cancer-related, or whether they are general/pre-existing problems for which the patient should see or should already have seen their GP.

Data 12

Training session in the DT+PL

Dr A: if something is related to oncology – there is no discussion about that – that is very clear that it belongs with us. That is not the point. The point is, is everything that surfaces here related to oncology and that is not easy to determine, really.

Cancer-related problems clearly belong within the oncologists' 'brief', "there is no discussion about that – that is very clear that it belongs with us". However, it is not always easy to determine this.

Apart from this, since these oncologists have not been trained to deal with psychosocial issues, it is also difficult for them to determine whether the patient suffers from psychological problems:

Data 13
Training session in the DT+PL

`Dr A: there are things that I think, yes, that is not at all, that is not at all what we have been trained for. On top of everything else […] I am not competent to judge that; I am not able to judge if someone has psychological problems.`

It may be concluded that there does not seem to be a clear consensus among the doctors in this study as to the scope of their role vis-à-vis issues that lie outside the directly oncological/biomedical; they disagree about whether the discussion of psychosocial issues should be included as an 'end' of the follow-up consultation, and do not feel optimally prepared to do so. Even knowing whether or not they should refer the patient to a psychologist is difficult, because oncologists have not been trained to distinguish between 'normal' psychological distress, and distress which requires expert treatment. The doctors' reluctance to engage in psychosocial and psychological issues mirrors the findings of other studies, which indicate that doctors tend to shy away from the discussion of issues outside the physical domain (see e.g., Beach et al., 2005; Cameron et al., 2015; Ford et al., 1996; see also Introduction).

Some patients, however, indicate that they would welcome the discussion of psychosocial distress in follow-up, as is illustrated in Data 14, where a patient complains that the psychosocial stress involved in being diagnosed with and treated for cancer is largely ignored in the hospital.

Data 14
Interview Patient Dr A

`Pt: The psychological side that-that is not eh dealt with. It does not get asked about either. […] In one fell swoop your world gets turned upside down. And that is totally ignored […] That has a huge impact – cause that's what it does. And I-I now you also meet people who are in the same situation and it turns out to be like that for everyone`

So, the patient-perspective may include the monitoring of psychosocial distress as an end of the follow-up cancer consultation.

There may be a tension here: on the one hand there is the doctors' reluctance to discuss psychosocial issues, based on practical issues of time, and epistemic issues around their perceived lack of expertise on the topic. On the other hand, there are the wishes of some of the patients as well as policy demands: as was discussed in the Introduction to this thesis, in the policy documents that provide the regulatory framework for the follow-up cancer consultation the monitoring of patients' psychosocial condition is formulated as an integral part of the follow-up process (see e.g., Epstein & Street, 2007 and Integraal Kankercentrum Nederland, 2010), and the DT+PL has been introduced to facilitate this (Integraal Kankercentrum Nederland, 2010).

If included in the 'standard' Ends of the follow-up cancer consultation, the monitoring of psychosocial issues will have impact on the roles of the doctors, the Act sequence, and possibly on the timing of the consultations, more time being needed to include extra topics in the discussion (see chapters 5, 6 and 7).

2.4 Act sequence

The Act sequence (or move structure; Swales, 1990) of a speech event refers to the default elements that are essential to a speech event, and their default order. Heritage & Maynard (2006b) state that investigating the overall structure of doctor-patient interaction "is valuable in providing access to understandings about the nature of the medical visit which are drawn upon by physicians and patients in their joint management of its progress" (p. 15). Robinson (2003) argues that the organisation of acute GP consultations and the production of communicative behaviour by doctors and patients involved in these consultations is shaped by the medical activities that together constitute the core of those consultations: "establishing the reason for the visit, physicians gathering information (i.e., history taking and physical examination), physicians delivering diagnoses, and physicians providing treatment recommendations" (p. 27). Proposals for a default sequence of General Practice consultations have been suggested in e.g., Byrne & Long (1976), Heritage & Maynard (2006b) and Ten Have (1989). The proposals are very similar and include – in this order – slots for opening, complaint, examination or test, diagnosis, treatment or advice and closing of the consultation.

As observed by White et al. (2013), the follow-up consultation shares a number of characteristics with the 'ordinary' GP consultation and other types of consultations within the genre of medical consultations. It also has a tightly organised format with a particular sequential structure. However, there are some crucial differences. Table 1 shows how the default Act sequence of the follow-up cancer consultation compares with the various proposals for the GP consultation.

Ten Have (1989) *GP visit*	**Byrne & Long (1976)** *GP visit*	**Heritage & Maynard (2006b)** *GP visit*	**White et al. (2013)** *Follow-up surgeon-patient visit*	**Current study** *Follow-up head-and-neck cancer consultation*
Opening	I: Relating to the patient	Opening: doctor and patient establish an interactional relationship	Activity 1: Re-establishing clinical relationship	Opening: may involve chitchat, summary of medical history and/or previous tests
Complaint	II: Discovering the reason for attendance	Presenting complaint: the patient presents the problem/reason for the visit	Activity 2: Establishing patient's description (and perspective) of their problem since previous visit	Anamnesis introduced by HAY? question: aim is not to find out what is wrong with the patient, but to determine whether the patient is still cancer-free and coping with after-effects
Examination or test	III. Conducting a verbal or physical examination or both	Examination: the doctor conducts a verbal or physical examination or both	Activity 3: Gathering further information through verbal and/or physical examination	Physical examination: to check for recurrence
Diagnosis	IV. Consideration of the patient's condition	Diagnosis: the doctor evaluates the patient's condition	Activity 4: Reformulating the problem	Discussion of findings, reassurance or announcement and rationalisation of further tests
Treatment or advice	V. Detailing treatment or further investigation	Treatment: the doctor (in consultation with the patient) details treatment or further investigation	Activity 5: Proposing next steps	Advice and/or next steps in terms of scheduling further tests or referrals
Closing	VI. Terminating the consultation	Closing: the consultation is terminated	Activity 6: Closing the consultation	Wrap-up and closing with timeline for next visit

Table 1 Comparison of default Act sequences in different types of consultations

The phases in the Act sequence of the follow-up cancer consultation can be described as follows.

Opening

Whereas in initial GP or other doctor visits the opening is geared to *establishing* a clinical relationship (Byrne & Long, 1976; Heritage & Maynard, 2006b), in the repeat or return visit, such as the follow-up cancer consultation, it is aimed at *re-establishing* the relationship before moving to the reason for the visit (cf. White et al., 2013). The steps involved are very similar. Robinson (2013) states that four tasks typically precede “the initiation of the ‘first topic’” (p. 261) – i.e. complaint – in medical consultations: “1. greeting, 2. securing patients’ identities, 3. retrieving and reviewing patients’ records, and 4. embodying readiness [through] e.g. sitting down and facing one another” (p. 261).

In relation to this, it is important to bear in mind that the Act sequence of the transition from social to medical/institutional context seems to develop differently in the Dutch data than in the US/UK (see e.g., Coupland et al., 1994; Robinson, 1998). An important, cultural, element in this is the way in which doctor and patient encounter each other. In the US/UK context, the patient enters the doctor’s office, where the doctor is seated behind his/her desk, or the patient is seated in an office, and the doctor enters (see e.g., Coupland et al., 1994; Robinson, 1998). All four of Robinson’s (2013) transitional tasks are then conducted in the doctor’s office. However, in The Netherlands, doctors typically first consult patient’s files at the computer in their consultation room (task 3), then fetch the patient from the waiting room and walk with the patient back to the consultation room. At this point greetings have been exchanged (task 1) and patient’s identity has been established (task 2). The doctors report that in the short walk from waiting room to consultation room, doctor and patient tend to engage in informal chat, a form of social communication which Malinowski (1923/1946) refers to as ‘phatic communion’: “in which ties of union are created by a mere exchange of words”, bringing hearer and speaker “into the pleasant atmosphere of polite, social intercourse” (Malinowski, 1923/1946, pp. 315-316; cf. Coupland et al., 1994). This ‘phatic communion’ – which may include, e.g. talk about the weather, or about the trip to the hospital – is needed, according to Malinowski, to avoid what he calls an ‘unpleasant’ absence of talk, since “another man’s [*sic!*] silence is not a reassuring factor”(1923/1946, p. 314).

Upon entering the room, there is what Coupland et al. (1994) term ‘dispositional communication’ (p. 98), through which the physician invites the patients to hang up their coat and sit down, and patients and companions talk about where to sit, and about papers they are taking out of bags and pockets. All then sit down, the doctor at one side of the desk, and the patient (and their companion) at the other, embodying readiness to get down to the business at hand, the consultation proper (task 4). In some cases, the doctor may then summarise the patient's medical history or refer to previous tests, to establish they are 'on the same page'. At this stage, all four of Robinson's (2013) transitional tasks have been completed, and doctor and patient are ready to initiate first topic.

Anamnesis

As mentioned before, where in acute GP visits or initial specialist visits, anamnesis is directed at diagnosis of the patient's complaint, in follow-up head-and-neck cancer consultations it is directed at finding out how the patient is doing, and focusses on cancer recurrence and the management of after-effects (see 'Ends'). The follow-up consultation is by definition a return visit, and the interaction reflects this, with references to previous visits and the time between visits. The doctor typically opens the anamnesis by asking an open question, usually a form of 'how are you?', inviting the patient to give a gloss of his/her condition (see 'Norms' below and Chapter 3).

Physical examination

Usually following the verbal anamnesis, doctor invites patient to the examination chair for a physical examination. During the medical check, physicians typically give a running commentary of what they see and feel, emphasising that what they are finding is OK (see also Heritage & Stivers, 1999), or commenting on findings that might require further tests.

Reassurance, referrals and ordering of further tests

The combined results of anamnesis and physical examination[19] can have a number of outcomes. Lack of symptoms and/or abnormalities may lead to a confirmation of wellness, and the doctor reassuring the patient that at this point in time they are free of symptoms of cancer. Some symptoms require no immediate action, and doctor will inform patient that they themselves need to

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[19] … and where applicable the results of routine tests. However, in the current study consultations that discuss test results have been excluded (see Chapter 1).

monitor those symptoms, which in any case will be revisited at the next consultation. Lastly the findings may lead to the conclusion that there are reasons for worry and therefore for ordering further tests, or for referral to specialist care for the treatment of after-effects.

Advice and next steps

If patients have questions about medication, diet, care for wounds or other issues, doctors will often at this stage summarise their advice on how to deal with them and answer any remaining questions patient or companion may have. If relevant, doctors may at this stage discuss possible long-term effects of disease and/or treatment, which patients should be aware of. Doctor and patient may discuss bad habits the patient is seen as needing to give up (e.g., smoking), or good habits (e.g., exercise) the patient is seen as needing to develop/keep up. Also, typically, doctors will warn patients to make an extra appointment 'if anything changes', euphemistic shorthand for 'if you experience worrying symptoms'. If relevant, doctors at this stage explain what further tests need to be ordered/what other care-givers patient needs to see and why, and they discuss next steps in terms of scheduling referrals and further tests.

Wrap-up and closing

Doctor and patient discuss when patient is due for the next follow-up consultation. Depending on how long ago treatment was completed, combined with the chances of recurrence and/or the needs of the patient, the next follow-up consultation is scheduled a few weeks up to twelve months after the current one. If patient has been treated by more than one doctor (e.g., surgeon and dermatologist), patients often see the doctors alternately. Patient is asked to make the appointments with the staff at the reception desk. At this stage of the consultation often some phatic chitchat occurs, up to the exchanging of goodbyes.

The elements in the Act sequence described above are typical for the follow-up consultation. They are closely dependent on and related to the Ends or goals of the interaction. The acts of anamnesis and physical examination are aimed at monitoring for signs of recurrence and management of after-effects, whereas the acts of reassurance and advice are instrumental in relieving patients' anxiety. In addition, as White et al. (2013) observed, the stages of the interaction crucially inform each other. Conclusions on the necessity of referral or further tests can only be drawn on the basis of anamnesis and physical examination. However, it is important to note that the Act sequence as described here does not always occur in this clear-cut fashion, one distinct element following another in a specific order. This was observed by Ten Have (1989), who therefore calls this sequence an ‘ideal’ sequence, “because one observes many deviations from it that seem to be quite acceptable to the participants” (p. 118). This observation is confirmed by Heritage & Maynard (2006b), who state that doctor and patient may “break out of and return to particular activities” (p. 15): elements may occur in a different order, elements may merge, overlap, come back or be skipped, and they may at any point be interrupted by informal chat, more or less situationally relevant narratives, or medically oriented question-and-answer sequences initiated by doctor, patient or companion (see *Norms* below). Also, in the current data the actions relevant to reassurance, advice and wrap-up mostly seem to be merged into one ‘rounding off’ phase of the consultation.

2.5 Key

The Key of the interaction is the “tone, manner, or spirit in which an act is done” (Hymes, 1972a, p. 62). The Key may be sombre, cheerful, serious, playful, etc. It may be indicated, for instance, by a more or less formal register, non-verbal signals such as smiles or frowns and posture, and paralinguistic features such as tone of voice (cf. Saville-Troike, 2003).

As we have seen in ‘Ends’ above, there are a number of aims in the follow-up consultation, which affect the Key or tone of the consultation. Two aims stand out: firstly, to rule out new malignancies, and thereby to minimise the patient’s anxiety about their illness; secondly, to monitor the possible after-effects of treatment and illness. These aims lead to a mixture of orientations in the consultation. On the one hand, there is an orientation towards *distress*, e.g., anxiety about recurrence, discomfort through physical after-effects, and psychosocial problems involving the condition of being a cancer survivor. On the other hand, there is an orientation towards *wellness*, e.g., the continued absence of malignancies, diminishing of after-effects, plans for a healthier life-style. This may lead to the combination or alternation of a negative and a positive Key in the interaction, which are co-constructed by the participants. (See Chapter 4 for a detailed discussion of the Key).

2.6 Instrumentalities or Message forms

In Hymes’ (1977) taxonomy of parameters of speech events, the parameter ‘Instrumentalities’ includes both ‘forms’ of speech (varieties, dialects and styles) and ‘channels’ of communication (oral, written, semaphoric, etc). Saville-Troike (2003) distinguishes two ‘channels’ (vocal and nonvocal) which each have two ‘codes’ (verbal and nonverbal): verbal/vocal (spoken language), nonverbal/vocal (paralinguistic and prosodic elements), verbal/nonvocal (written language, sign language), nonverbal/nonvocal (silence, proxemics, eye behaviour and pictures).

In the follow-up cancer consultation – as in most other doctor-patient interactions – different Instrumentalities/Message forms occur side by side. First and foremost, there is verbal/vocal communication, with the participants in the consultation communicating in a variety of forms of speech, ranging from formal to informal, and from standard Dutch to various non-standard social and geographical varieties. Latin and medical jargon will occur when discussing specific medication, malignancies and treatments. Nonverbal/vocal communication plays a prominent role during the physical examination part of the consultation. For example, patients are asked to make a certain sound, e.g., ie-ie-ie (‘ee-ee-ee’), to enable doctor to see what is going on in patient’s throat: the doctor demonstrates the sound, then patient mimics it. Also, patients sometimes indicate discomfort by sounds like uh-uh-uh when during the physical the physician feels in their mouth or feeds a camera down their nose. Nonverbal/nonvocal communication in the consultation includes e.g., filled pauses in question-answer sequences, with doctors typing up a patient’s answer and thus signalling that they are holding the next turn at talk in spite of leaving an ‘utterance-free space’ or gap in verbal communication (Psathas, 1990), gaze, position and body language.

Verbal/nonvocal communication occurs when patients bring written material into the consultation (e.g., letters from other physicians which are handed to the doctor to read, or lists with questions for the doctor, which are shown to the doctor, shared and discussed) and when doctors make use of patients’ computer-based medical file. This file is used as a point of reference for the physician to check patients’ status, remind themselves of who else is involved in their treatment, etc. Also, doctors fill out patients’ medical files ‘live’, as the consultation progresses, sometimes typing while talking or listening, sometimes announcing they are going to type and taking a time-out in the consultation, to concentrate on accurately filling out the file. When the data were collected for the current study, the hospital had just transferred from hard-copy files to computer-based files, and the doctors were still getting used to the change. They frequently shared this with the patients, joking about their inability to type, as illustrated in Data 15.

Data 15

Consultation Dr D

P1		(8.7) ((Dr working on computer))	(8,7) (Dr op computer bezig))
	Dr:	you see (.) all (.) typing that is all new (4.1) ((Dr types))	u ziet (.) allemaal (.) typen dat is allemaal nieuw (4,1) ((Dr typt))
P2	Dr:	and I cannot type at all so eh	en ik kan helemaal niet typen dus eh
P3	Pt:	no↑	nee↑
P4	Dr:	=takes-takes a bit longer	=duurt-duurt even langer

Dr D here announces and demonstrates the use of the computer and apologises for the delay caused by his inability to type.

Chapters 5, 6 and 7 will discuss how the introduction of a new Instrumentality (the verbal/nonvocal DT+PL) affects the follow-up cancer consultation as a speech event.

2.7 Norms

It is assumed that the way persons interact in everyday life spills over in the way they interact in institutional environments (see e.g., Maynard & Heritage, 2005). However, the institutional context will influence aspects of talk, such as turn-taking patterns (see e.g., Flowerdew, 2013), and otherwise influence the affordances and constraints of the interaction (see Drew & Heritage 1992), such as constraints on what the participants in the action see as allowable contributions in the context. In Hymes' and Saville-Troike's categorisation of elements of the speech event, these affordances and constraints fall in the category of 'Norms'.

Under 'Norms', Hymes (1972a) and Saville-Troike (2003) subsume norms for interaction and norms of interpretation. Hymes (1972a) defines norms of interaction as "the specific behaviours and proprieties that attach to speaking" (p. 63), e.g., the turn-taking mechanisms of the interaction (e.g., who can ask questions, who can interrupt whom), where participants sit or stand relative to each other, the direction of gaze, touch, etc. Violations of these rules are experienced by the participants as "'impolite' or 'odd' in some respect" (Saville-Troike, 2003, p. 123). The norms of interpretation encompass "all the other information about the speech community and its culture which is needed to understand the communicative event" (Saville-Troike, 2003, p. 124).

Both norms of interaction and norms of interpretation are strongly related to and dependent on the Participants, the Ends and Act sequence of a speech event, *hoc loco* the follow-up cancer consultation.

Norms related to Participant structure

The default participant structure of the follow-up cancer consultation involves two participants, the physician and the patient. Therefore, the default interaction is organised around a dyadic turn-taking mechanism (Sacks et al., 1974), with doctor and patient in turn performing the roles of speaker and addressed recipient (Goffman, 1979).

When a companion is present at the consultation, the interaction is no longer dyadic, but more complex. The companion usually starts out as (and often remains throughout the consultation) a ratified but unaddressed recipient in the social encounter (Goffman, 1979), taking no active verbal part in the consultation. However, s/he may actively enter the interaction as a ratified speaker and addressed recipient at any point – either spontaneously or at the invitation of one of the other participants –, which changes the 'footing' (participation framework, alignment of participants) of the interaction (Goffman, 1979).

Interruptions, e.g., in the form of doctors' telephones ringing or colleagues entering the room with questions, take temporary precedence over the dominant interaction, i.e., the consultation in progress. The footing changes, with patient and companion becoming overhearers, and physician and 'interruptor' alternating between speaker and addressed recipient roles. At times doctors will even briefly leave the consultation room to deal with the question or emergency announced by phone or colleague. When the interruptive interaction has been completed, the consultation continues from the point of interruption (cf. Goffman, 1979), and the original participant structure is resumed.

Norms related to Ends and Act sequence

In the anamnesis phase of the consultation, the aim of the interaction is to find out how the patient is doing, how s/he is coping with medication and after-effects and whether the cancer has recurred. In this phase, doctors typically ask a series of interlocking question, which are, as Frankel (1995) writes, "designed to elicit information that is complete and accurate enough for the clinician to arrive at a conclusion" (pp. 247-248).

In the current dataset, the opening of the anamnesis phase consists of the doctor asking the patient an open question: *Hoe gaat het met u?* 'How are you?'. This creates an opportunity for the patient to select a first topic, usually a gloss of their general condition, where relevant followed by a complaint (for a discussion of 'How are you?', see Chapter 3). It gives the patient the opportunity to present any problems they might have (cf. Heritage, 2010). At this stage patients sometimes tentatively insert lay diagnoses for their complaints. However, while to the doctor the symptoms are relevant at this stage, the patient's explanation of them may be less so, since this may lead to a premature discussion of conclusions, before all the facts (to be gathered from anamnesis and physical examination) are in (see e.g., Gill & Maynard, 2006; see also Chapter 7).

There seem to be 'preferred slots' in the Act sequence for patients to ask questions. During anamnesis and the physical examination doctors deal with the basic aim of the consultation, i.e., checking for cancer (see e.g., Gill & Maynard, 2006). Frankel (1990) and Ten Have (1993) claim that patients very rarely ask questions during this stage of the consultation, and this is also shown in the current study: only in three out of the 28 consultations does a patient ask a spontaneous question during anamnesis. Both doctor and patient are aware that this is the phase where doctor needs to collect data, and patients seem not to want to disrupt the process (Gill & Maynard, 2006).

This changes when anamnesis and the physical have been completed and the consultation has reached the 'reassurance' and 'advice' phases of the consultation. This is when doctors aim to take away patients' anxiety if they have found no signs of cancer, where next steps, such as extra tests, are discussed if there are symptoms that warrant that, and where practical issues are discussed, such as the treatment of wounds. At this point in the Act sequence, patients and companions regularly ask questions (see e.g., Frankel, 1990), which range widely from practical questions, such as asking more detailed instructions on how to look after wounds (see Data 9), to anxious questions about possible recurrence. Patient questions in this phase can count on an immediate response from the doctor.

As discussed in the section on 'Act sequence' above, the stages of the consultation do not always occur in the standard order. Sometimes doctors immediately respond to concerns by the patient during anamnesis with reassurance or advice, which may temporarily turn the typical question-answer structure of the anamnesis into more of an informal conversation. Alternatively, new symptoms may be offered by patients in the later stages of the consultation, which may temporarily turn the interaction into the question-answer structure of anamnesis.

As is to be expected in an institutional context such as the follow-up cancer consultation, the interaction is usually task-oriented. Earlier research into doctor-patient interaction shows that doctors – especially in question-answer sequence of the anamnesis stage of the consultation – tend to respond to patient answers with more questions, rather than tokens of affiliation (cf. Frankel, 1984, Ten Have, 1990, Easter & Beach 2004). However, in the current data, elements of ordinary conversation, such as affiliation and chitchat, occur at all stages of the consultation, although most frequently outside the anamnesis phase (cf. Ainsworth-Vaughn, 2001).

3.0 Conclusion

As the analysis above has shown, the context of the follow-up head-and-neck cancer consultation is a strongly regulated work environment, an institutional setting. The interaction in the follow-up cancer consultation can therefore be seen as an instance of institutional discourse, talk-at-work, with its specific Participants, Ends, Act sequences and Norms for interaction. All these elements can be seen to influence the interactional patterns that participants orient towards in follow-up cancer consultations.

The Participants in the routine follow-up cancer consultation include the doctor, the patient (who has finished curative treatment and – in the current selection – has been cured of the tumour, but is still at risk of recurrence and morbidities from the cancer and its treatment) and (optionally) the companion. The follow-up cancer consultation is a type of return visit (see Data 1), which implies that over time the patients, who are relatively inexperienced participants in this type of speech event at the outside, become more competent participants in the speech event as time progresses (see Data 2). The companion occasionally participates in the interaction, often to help patient to formulate problems or questions (see Data 5). The consultation has specific Ends (aims), i.e. to determine whether or not the cancer has returned and whether or not the patient is coping with any side effects. The Ends determine the Act sequence of the consultation: anamnesis and physical examination need to be conducted first, so that doctor can gather the information s/he needs to determine how patient is doing; with the information from these steps it is possible to move on to reassurance and/or discussion of further test, and advice/next steps. During the physical examination, doctors tend to give a running commentary of their findings, which often functions to already reassure the patient. The Act sequence and Ends of the consultation in their turn steer the Norms of interaction during the various phases of the consultation, with doctors asking questions during anamnesis to discover how the patient is doing, and patients mostly refraining from asking questions during anamnesis and physical, since this might obstruct the aim of checking for cancer. However, patients and companions feel free to ask questions in the reassurance and advice phases of the consultation (see Data 5), where it is important that they check that they understand the information the doctor is giving them, and that they get information or reassurance on issues that worry them. In the same consultation, positive and negative Key may alternate, depending on the (aim of the) topic under discussion at various points in the consultation.

Chapter 3: The transition from opening to anamnesis in follow-up cancer consultations: The ‘How are you?’ question revisited[20]

Prologue

This chapter is the result of a serendipitous finding during the transcription of the video-data of the standard follow-up head-and-neck cancer consultations collected for this project: all but one of the consultations opened in the same way, with a ‘How are you?’ (HAY?) question, the canonical opening of medical consultations that has been widely researched. What was striking, though, is that it seemed that all these questions were answered as requests for *medical* information. This outcome would not be in line with earlier research on ‘How are you?’ questions, which hinges on the ambiguity of the question between a social and a medical inquiry. The discrepancy between these earlier analyses and the first pre-theoretical intuitions about the data in the current study triggered a new, previously not envisaged research question (Edelsky, 1981), which will be the focus of this chapter.

1.0 Introduction

The transition from the opening phase of medical consultations to anamnesis is generally achieved by (a variation on) the question ‘How are you?’ (see e.g., Coupland et al., 1994; Frankel, 1995; Heritage & Robinson, 2006b; Rogers & Todd, 2010). Coupland et al. (1994) for instance, found that 94% of the consultations they recorded in a geriatric out-patient clinic opened with this question. In the institutional, medical setting of the doctor-patient consultation the ‘How are you?’ question then may be seen to function as a verbal contextualisation cue (Erickson & Schulz, 1981; cf. ‘bracketing’ device, Goffman, 1976) that physicians employ to signal and effectuate the transition from informal chit-chat towards the formal context of the consultation proper.

In non-institutional settings ‘How are you?’ questions tend to fulfil a phatic, almost ritual function, intended to achieve bonding, rather than that they are

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[20] This chapter is an adapted version of a paper that was published earlier as Van de Laaken, M. & Bannink, A. (2020) Openings in follow-up cancer-consultations: The ‘How are you?’ question revisited. *Discourse Studies 22(2)*: 205-220.

genuine inquiries into the other's state of health, as can be observed in e.g., informal conversations in the USA (see e.g., Coupland et al., 1992; Sacks, 1975). In his analysis of this type of question in informal social contexts, Sacks (1975) calls the question a 'greeting substitute', because it can both follow and replace an 'ordinary' greeting sequence. And like greetings, 'ritual' 'How are you?' usually appears in a reciprocal exchange sequence: as the first pair part of an adjacency pair that makes a second pair part sequentially relevant (Schegloff, 1986).

Informal, phatic 'How are you?' questions and their institutional (*hoc loco* medical) counterparts seem to be different moves, fulfilling different interactional functions. Openings of institutional events must be negotiated by the participants to ensure mutual orientation to the task-at-hand, and transitions from informal to institutional settings do not always proceed without a hitch. Ambiguity may arise with the question at the very beginning of medical consultations as to 'where we are' in the interaction (cf. Erickson & Shultz, 1981). The context may be interpreted by one (or some) of the participants as 'still social' and the question as a form of/invitation for (more) phatic communication, while others may interpret the context as 'now institutional'.

This potential for hybridity as to the function of the question has been widely reported for Anglo-Saxon medical contexts (mainly US and UK), showing that, since the boundary between the social and the medical context at the start of the medical consultation is fuzzy and permeable, the opening question is sometimes being interpreted and answered as social, and sometimes as medical (e.g., Coupland et al., 1992; Coupland et al., 1994; Frankel, 1984; Heritage & Robinson, 2006b). As mentioned in the Prologue, these findings contradicted the first intuitions about the data collected for this study and has triggered the investigation that follows.

2.0 Description of the data

The data for the current chapter consist of video-recordings of 28 standard follow-up head-and-neck cancer consultations, conducted at the outpatient clinic of the head-and-neck cancer department of the NKI (see Chapter 1). They are routine follow-up consultations, with 18 (64%) male, and 10 (36%) female patients, and conducted by four different physicians (9 for Dr A; 7 for Dr B, 6 for Dr C and 6 for Dr D).

A first quantitative analysis showed that all but one consultation in the dataset opened with a ‘How are you?’ question. Patient responses varied, as can be seen in Table 1 below.[21]

This table differentiates between responses that orient towards wellness and those that do not; responses that include a complaint/distress, and those that do not; responses that were prefaced by delay (in the form of filled and unfilled pauses, see below) and those that were not; and combinations of these features.

In the data only two patients immediately respond with a distress-oriented response to the question (category 7 in Table 1), directly formulating a complaint. Five patients responded with an unequivocal orientation to wellness, with no complaints surfacing in the rest of the consultation (categories 1 and 2). In the discussions of whether ‘How are you?’ questions and their responses can be seen as social/phatic or interactional/medical, earlier research has judged unequivocally positive and negative appraisals “to

	Patient’s reply orients towards:	Dr A	Dr B	Dr C	Dr D	Total	%	
1	Wellness with no delays, no complaints		2		2	4	14.8%	18.5%
2	Wellness with delay, no complaints			1		1	3.7%	
3	Wellness, complaints in same turn			2		2	7.4%	70.4%
4	Wellness, late complaint	2	1			3	11.1%	
5	Wellness with delay, complaints in same turn	2	1	1	1	5	18.5%	
6	Wellness with delay, late complaint	3	2	2	2	9	33.3%	
7	No wellness-orientation; complaints with delay	1	1			2	7.4%	7.4%
8	Hedge only, no wellness, no complaint				1	1	3.7%	3.7%
	Total	*8*	*7*	*6*	*6*	*27*	*100%*	*100%*
	No HAY?, direct complaint without prompting	1				1		

Table 1 Types of responses to the ‘How are you?’ question in standard follow-up cancer consultations

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[21] Patients’ responses were categorised independently by two analysts. In case of disagreement, discussion about the criteria led to consensus.

be more readily interpreted in a medical frame" (Coupland et al., 1992, p. 221), and as non-phatic. In the current data, these patients' initial gloss of wellness or distress, indeed, matches the information they give in the rest of the consultation, so there seems to be little reason to problematise these assessments.

In the majority of the cases, however, positive first glosses are combined with complaints: patients respond with an initial orientation towards wellness and then either immediately, in the same turn, or later in the consultation, voice a complaint (categories 3, 4, 5 and 6). This pattern mirrors the findings of Coupland et al. (1992), Coupland et al. (1994), Frankel (1995), and Heritage & Robinson (2006b), who observed that patients, immediately after claiming they are fine, frequently present problems, e.g., with troublesome symptoms, or side-effects and after-effects of the treatment they received. This prompted their position that in wellness-oriented replies to 'How are you?' questions that are followed by complaints, the first half of the response must be seen as oriented towards the social context rather than the medical one (e.g., Rogers & Todd, 2010), or at least as ambiguous between the two (Coupland et al., 1992; Coupland et al., 1994). This analysis seems problematic to us, as the patients in the current data appear to consistently orient to the medical context in their response to the question.
This has led to the research question for this paper: How can we be so sure that patients' responses are medically oriented, more specifically, is it possible to pinpoint dimensions of the global/institutional and local/interactional parameters of the consultations in the data that might account for this observation and provide reasons for the differences with earlier research?

To find an answer to this question, this chapter will focus on relations between the interpretation of the 'How are you?' question in the data and interactional and contextual features of the particular speech event they derive from:

- the interpretation of the question relative to the socio-cultural and institutional characteristics of the follow-up cancer consultation in the *Dutch* context;[22]

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[22] Apart from work being done by Stommel et al. (2018) on Internet consultations, as far as the author is aware no ethnographic or CA-inspired research has been done on the 'How are you?' question in The Netherlands.

- the interpretation of the question relative to the context of the *'return visit'*;
- the response to the question relative to the intrinsic complexity of the question in the follow-up *cancer* consultation.

3.0 The interpretation of 'How are you?' relative to the socio-cultural and institutional parameters of the encounter

The influence of culture, ethnicity and concomitant discourse patterns in medical encounters has often been researched, e.g., in an effort to identify barriers to establishing effective doctor–patient relationships (e.g., Schouten & Meeuwesen, 2006), but the author is not aware of any studies that offer an analysis of the socio-cultural and institutional dimensions of the organisation of the encounter itself as instrumental in the discursive construction of the opening of the speech event 'medical consultation'. The following paragraphs will use such an analysis to explore how routine procedures in the opening of the event may influence the interpretation of the 'How are you?' question.

Robinson (2013) describes four tasks that must be accomplished in order to establish a medical context: *1. greeting, 2. establishing identities, 3. checking records and 4. embodying readiness*. If the 'How are you?' question is asked before these tasks have been completed, Robinson argues, the boundary between the social and the medical is not clear (cf. Coupland et al., 1992; Coupland et al., 1994; Frankel, 1984; Heritage & Robinson, 2006b), i.e. the medical context has not yet been fully established and this increases chances for a social interpretation of the question. Tasks one, two and four from Robinson's list are enacted as *contextualisation cues* (Gumperz, 1992), interactional tools by which the interactants co-construct "that something new is happening" (Erickson & Shultz, 1981, p. 150). Contextualisation cues signal context changes and concomitant changes of 'footing' (participant alignment, e.g., speaker and hearer rights and obligations; Goffman, 1979) and include "changes in voice tone, pitch, and other features of speech prosody; changes in linguistic code, style, and topic; changes in the tempo and rhythmic organisation of speech and body motion; changes in gaze direction and facial expression; [and] changes in number of speakers and listeners" (Erickson & Shultz, 1981, pp. 148-149). Major transitions in situational contexts, such as the transition from an informal conversational setting to a formal institutional one, are usually marked by a great redundancy of contextualisation cues, clusters of them being used in tandem to mark, and thereby facilitate, the transition.

When in The Netherlands patients come in to see a physician, they meet in the waiting room. The doctor routinely checks the patient's medical record in the consultation room, then walks over to the waiting room and calls out the patient's name. Both parties shake hands,[23] exchange greetings and – often chatting on the way – together walk to the consultation room. This practice differs from the standard procedure in most US and UK contexts, where participants typically meet in the consultation room where either doctor or patient is already seated (see Chapter 2).

It may be concluded then that in the Dutch medical context of the current data the first three of Robinson's tasks – greeting, establishing identity, checking records – have already been accomplished when doctor and patient enter the consultation room. Task four – embodying readiness – is then performed through a cluster of, in some cases individually different, contextualisation cues. Typically, doctor and patient sit down on either side of the doctor's desk. The doctors often look at the screen while the patient sits down, conveying what Robinson (1998, p. 109) calls "the doctor doing bureaucracy", and thus establishing a clear medical context. They then turn to the patient and, making eye-contact, ask 'How are you doing?'.[24] They often add a temporal focus to the question on the time between the last and the current visit, (e.g., *intussen* or *in de tussentijd* = 'in the meantime'; cf. Coupland et al., 1994), referencing the context of the return visit (see section 4), a strategy which has been shown to make a medical interpretation of the question more likely (see e.g., Coupland et al., 1994). In addition, Dr B and Dr D often use the turn-initial discourse marker *zo* ('so') as a signal to the transition to a new context (Raymond, 2004) and marking the next point on the institutional agenda (cf. Bolden, 2009). Dr C briefly summarises patient's medical history before he asks the 'How are you?' question and, by focussing on this 'shared history', creates a clear medical context (cf. Heath, 1981; Coupland et al., 1994). Dr D typically asks the question while dividing his gaze between the patient at his desk and the computer screen that displays the patient's electronic medical record, and which he fills out during the consultation. By shifting his gaze back and forth between the patient and their record on screen Dr D is, as Robinson (1998, p. 105) notes, "shifting [his] engagement from patients disembodied to patients inscribed, or

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[23] This chapter describes the situation pre-Covid.

[24] The doctors all have their own ways of phrasing the 'How are you' question (*Hoe gaat het met u* = 'How is it going with you'*, Hoe is het* = 'How is it'*, Hoe is het met u gegaan* = 'How have you been'), but the different ways of phrasing do not trigger different interpretations or responses.

from patients in person to patients in bureaucracy", making a medical interpretation of the 'How are you?' question more likely. An illustration of the repertoire of contextualisation cues that occur in the data is shown in Data 1.

In this data the physician interacts with a patient who went through excision and radiotherapy of a carcinoma on the tonsil 11 months before the consultation.

Data 1
Dr B

[Participants have met in the waiting room, have exchanged greetings and have entered the consultation room]

P1	Dr: please sit down ((both sit down))	gaat u zitten ((beiden gaan zitten))
P2	Pt: okay (.)	oké (.)
P3	Dr: ((glances at computer while moving her chair closer to desk; smiles and makes eye contact with Pt; maintains eye contact throughout)) so (.) it is almost six months ↑ago	((werpt blik op computer terwijl ze stoel dichter naar bureau schuift; glimlacht en maakt oogcontact met Pt; houdt voortdurend oogcontact)) zo (.) het is een half jaartje ↑geleden
P4	Pt: yes	ja
P5	Dr: how have you been? (.) ((folds hands before her))	hoe is het met u gegaan? (.) ((vouwt haar handen voor zich))
P6	Pt: ehm well okay I guess (0.3)	ehm nou goed wel (0,3)
P7	Dr: ((nods))	((knikt))
P8	Pt: °I eh° (0.3) have gained a little weight=	°ik eh° (0,3) ben iets aangekomen=
P9	Dr: =okay=	=oké=
P10	Pt: =with d:fficulty	=met m:oeite
P11	Dr: yes	ja
P12	Pt: but okay	maar goed
P13	Dr: eating is still a little difficult↓ (0.2)	eten kost nog wel wat moeite↓ (0,2)
P14	Pt: yes with some things it is	ja met sommige dingen wel

In this data the doctor uses a cluster of verbal and non-verbal contextualisation cues to mark the transition to a medical context: she glances at the screen, she establishes eye contact with patient, she uses the discourse marker *zo* ('so'), which according to Bolden (2009, p. 974) "demonstrates that speakers [...] indicate the status of the upcoming action as 'emerging from incipiency' rather than being contingent on the immediately preceding talk". She also explicitly refers to the time that has gone by since patient's last visit 'it is almost six months ↑ago', which highlights their shared history of medical encounters. Only then, after patient has accepted the timeframe with 'yes', does she ask the 'How are you?' question – with a time-lapse marker in the tense form: *hoe is het met u gegaan* (lit: 'how has it gone with you', gloss: 'how have you been'). Patient responds to the question with an overall self-assessment 'okay', which, because of the delay ('ehm well') and the hedge 'I guess', cannot be marked as unequivocally straightforward. Patient then elaborates by saying he has gained weight – a positive signal in the medical sense in head-and-neck cancer patients. The choice of weight-gain as a topic here shows that patient's initial gloss should be interpreted as a medical orientation to the 'How are you?' question. As patient himself adds (P10, P14): the weight gain was not easy (eating is still difficult), due to after-effects of the treatment.

Data 1 shows that due to the doctor's use of a wide range of multimodal cues to mark the transition to the medical context, the 'How are you?' question, constituting the transition to the anamnesis (i.e. the business at hand of the consultation), is solidly embedded in the medical context. Patient's response – a hedged positive gloss followed by a next-turn elaboration – shows a clear alignment with this orientation.

To summarise, the medical interpretation of the 'How are you?' question in the dataset is supported by the density of multimodal contextualisation cues that routinely accomplish three out of four of the tasks that Robinson (2013) sets out for the creation of a medical context before the question is asked. This makes the boundary between the social and medical context in the dataset much less fuzzy and permeable than in the Anglo-Saxon (US and UK) contexts that were reported on in earlier research.

4.0 The interpretation of 'How are you?' relative to the context of the 'return visit'

The follow-up cancer consultation is by definition a *return visit* (cf. Gafaranga & Britten, 2005; Heath, 1981; Robinson, 2006). This feature of the encounter has an impact on e.g., what questions are relevant and how they are formulated. As illustrated in Data 1, the 'How are you?' questions in the data are often accompanied by a time marker which stresses the 'return' aspect of the visit. In the dataset doctors referred to this aspect in 19 out of 28 consultations. In six cases patients also refer to the return-visit context in their answers. These time markers steer the discourse to information on how the patient has been since their last visit to the doctor, through references to relevant *time periods* by means of phrases like *de laatste tijd* ('lately') and *in de tussentijd* ('in the meantime'). In this way doctors and patients discursively co-construct the medical context, as is illustrated in Data 2.

The patient in Data 2 had a laser excision of a melanoma on the head three months before followed by two operations, including excision of the lymph nodes in the neck a month later.

Data 2

Dr A

[Participants have met in the waiting room, have exchanged greetings and are entering the consultation room]

P1		((footsteps in the corridor))	((voetstappen in de gang))
P2		((Dr comes in and holds door open; points at chair))	((Dr komt binnen en houdt deur open; wijst naar stoel))
	Dr:	you may sit down here	Dr: u mag hier gaan zitten
P3		((Pt and Cp come in and sit down))	((Pt en Cp komen binnen en gaan zitten))
P4		((Dr walks to chair [((sits down and looks at Pt))	((Dr loopt naar haar stoel [((gaat zitten en kijkt naar Pt))
	Dr:	[how have you been doing in the meantime↑	[hoe gaat het met u intussen↑
P5	Pt:	((looks away from Dr)) ochch ((grins))	((kijkt weg van Dr)) ochch ((grijnst))
P6	Dr:	((moves chair closer to desk)) in the circumsta:nces↑ (.)	((schuift stoel aan)) naar omstandighe:den↑ (.)
P7	Pt:	[much better than the last time [((smiles; looks away))	[stuk beter dan de vorige keer [((glimlacht; kijkt weg))
P8	Cp:	[((looking at Pt) [((smiling at Dr))	[((kijkt naar Pt) [((glimlacht naar Dr))
P9	Dr:	ye:s↑	ja: ↑
P10	Pt:	↓yes ((turns to Dr)) (1.2) ((no longer smiling, but looking serious now)) .hh no[: it's go]ing eh:m	↓ja ((kijkt naar Dr)) (1,2) ((glimlacht niet meer, maar kijkt serieus)) .hh ne[e: 't ga]at eh:m
P11	Dr:	[tell me]	[vertel eens](1,6)
P12	Pt:	((coughs)) (1.6) as far as this is concerned completely fine ((points at left side of head)) as far as I can tell	((kucht)) (1,6) wat dit betreft helemaal goed ((wijst naar linkerzijkant hoofd)) naar mijn idee

In Data 2 the physician references the context of the return visit with the phrase *intussen* ('in the meantime'), which she attaches to her question 'how is it going with you'. Patient first responds with a vocal hedged delay, 'ochch'. At the same time he grins at the doctor, but he also looks away, apparently not committing himself to a clear response. The doctor interprets patient's reaction as a trouble premonitor (Jefferson, 1980, 1988) and qualifies her original question, making it more specific by referring to the 'circumstances' (P6) of the patient, who has only recently undergone operations to remove a melanoma on his skull and lymph nodes in the neck. Patient mirrors the doctor's orientation to the return aspect of the encounter with a temporal reference of his own, to the last time he saw doctor: 'much better than the last time', before continuing with more details of his medical condition (P10-12).

To summarise, the references by both participants to the time aspect of the return visit and relevant medical circumstances, plus patient's layered response show that from the very start patient orients towards the medical context of the encounter.

5.0 The response to 'How are you?' relative to the intrinsic complexity of the question for cancer patients

Just as in earlier research on the subject, patients in the data of the current study tend to begin their answers to doctors' 'How are you?' openings with a holistic positive gloss, even if they disclose various complaints and troubles in the same or following turns. The presence of the positive gloss is often interpreted as evidence for the reply to be (partly) social/phatic rather than medical and/or as evidence for the idea that the troubles resistance which is reported to be typical of ordinary interaction is spilling over into the medical consultation (Coupland et al., 1992; Coupland et al., 1994; Heritage & Robinson, 2006b; Rogers & Todd, 2010). It is not seen as truthful and informative, but as a social gambit, which is (later) followed by the 'real' answer: the complaint. As observed above, this is argued to be the result of the ambiguity of the status of the 'How are you?' question, with the patient interpreting the question as a social inquiry (Coupland et al., 1994; Rogers & Todd, 2010).

However, in the context of the follow-up cancer consultation the combination of a positive gloss followed by a complaint may have a different cause altogether: for cancer patients, formulating an answer to a How are you? question may not be completely straightforward (similarly to e.g., geriatric patients; see Coupland et al., 1992), for various reasons.

First, it is not always easy to determine what exactly the question refers to: does it point to the patient as defined by their disease – so restricted to the area affected by and treated for the malignancy? Does it refer to the after-effects of the treatment, to the patient's psychosocial situation, or is it meant holistically – referring to both the patient's biomedical and psychosocial condition?

Moreover, just as in ordinary conversations, patients need to decide whether the hearer – in this case the doctor – is, at this point in time, the person they wish to share this information with, and whether the hearer is willing and able to deal with their response (Sacks, 1975). So patients need to decide which particular aspect of their physical/mental/emotional condition – whether good or bad – they wish or need to share with this particular physician at this particular moment in this particular consultation: are troubles that have been discussed and treated on earlier occasions still or again relevant? Do they want to share psychosocial problems with their oncologist, or would they prefer to discuss them with their loved ones, their GP, or another professional? Is the small side-effect worth mentioning, or will they simply cope?

And finally, answering a 'How are you?' question in a follow-up cancer consultation is always related to the context of (recently) having been treated for cancer, which conjures up all sorts of difficulties in terms of how to formulate the answer: how is the patient doing compared to what? Compared to how the patient felt before they had cancer, after diagnosis, directly after treatment, at the last follow-up consultation? So the question would need to be interpreted in relation to time and circumstances. Doctors generally acknowledge this patient conundrum, as is illustrated in Data 2 above, where the doctor makes specific reference to the 'circumstances', i.e. the fact that the patient has very recently been operated on to remove a melanoma, to pinpoint the scope of the question. Patient, then, interprets the question and explicitly formulates his answer as compared to his condition at the last visit to doctor, 'much better than the last time'.

But these 'circumstances' can also be interpreted more broadly, to include the wider social and biomedical circumstances of patients. Coupland et al. (1992) report that the elderly people that were interviewed in their study, when asked how they were, responded *in relation to their circumstances*: being very old, they suffered from the complaints elderly people tend to suffer from, which both they themselves and the interviewers were well aware of. So, a positive response would be given, taking into account the baseline of 'positive' that can be held to apply to the very old (cf. Bredmar & Linell, 1999). Cancer patients in follow-up consultations might make similar judgments when answering 'How are you?' questions: a positive reply might take into account the baseline of 'positive' that is relevant and to be expected in the circumstances of recovering from cancer.

Thus, when patients give seemingly contradictory answers to the 'How are you?' question, they may be conveying exactly what they mean and feel – i.e. on the whole and in the circumstances they are/feel OK, but/and they suffer from one or more complaints (cf. Heath, 1981). This might simply be because there is no unequivocal answer to be given: under the circumstances they may generally be doing relatively OK, but there may (still) be specific issues (e.g., after-effects, problems with medication, anxiety) that distress them, as is illustrated in Data 3.

The patient in this data had an excision and radiotherapy of a tumour in the supraglottis three years and six months ago.

Data 3
Dr B

[Participants have met in the waiting room, have exchanged greetings and are entering the consultation room]

P1		((footsteps in the corridor))	((voetstappen in de gang))
P2		((Dr walks in, invites Pt in with a gesture))	Dr komt binnen en wenkt Pt naar binnen
P3	Dr:	please sit down	gaat u zitten
P4		((Pt walks in))	((Pt komt binnen))
P5		((Dr walks to desk and sits down))	((Dr loopt naar tafel en gaat zitten))
P6		((Pt hangs up coat and sits down))	((Pt hangt jas op en gaat zitten))
P7	Dr:	((glances at screen, types a short phrase, looks at Pt)) so, how is it ↓go:ing with you↑	((kijkt naar scherm, typt korte frase, kijkt naar Pt)) zo, hoe ↓gaa:t het met u↑
P8	Pt:	well in general it is going fai:rly OK (.) ((sniffs)) I've just got eh am s- very tired	nou over het algemeen gaa:t het wel (.) ((snuift)) ik heb alleen eh ben z- heel moe
P9	Dr:	hm-m (1.0)	hm-m (1,0)
P10	Pt:	and I still have (.) and that is getting worse and ↑worse (.) a lot of pain in my throat and neck	en ik heb nog steeds (.) en dat wordt steeds ↑erger (.) heel veel pijn in mijn hals en nek

When doctor and patient have seated themselves at either side of doctor's desk, embodying readiness, the physician opens with the discourse marker 'so' as a cue to indicate a shift to the next topic (Raymond, 2004; Bolden, 2009), before 'how is it go:ing with you', with strong emphasis on the main verb. Patient delays his answer with 'well' – a complexity marker, signalling that the answer may not be equivocal or simple to give (Mazeland, 2016) – and formulates a layered answer, giving a moderately positive gloss ('in general things are fairly OK') of his general condition. This references a holistic overall assessment of his condition, indicating that – within the frame of normality of having been treated for cancer (cf. Bredmar & Linell,1999) – he is doing reasonably well. Then, preceded by delay in the form of a short pause and a sniff, patient limits the scope of the positive gloss with 'I've just got', delay ('eh'), and a first complaint, 'only [I] am s-very tired', thus creating an exception to his expression of general relative wellness. Doctor responds with a continuer ('hm-m'), inviting patient to elaborate, and patient then adds another complaint. By constructing this complex response – combining a positive gloss followed by specific complaints – patient negotiates the intricacies of the 'How are you? question in relation to his situation, which can only be done justice to by means of this seeming contradiction.

Further evidence that the patients in the current dataset orient towards the complexity of answering their doctors' 'How are you?' questions is reflected in the fact that most wellness-oriented patient responses begin with a form of delay (15/24), consisting of unfilled pauses and pauses filled by e.g., 'ehm' and 'well' (see Data 1 and Data 2). This is even more salient for responses that are later followed by a complaint (14 delayed responses out of a total of 19 wellness-oriented responses that are followed by a complaint). Delay has been argued to preface dispreferred responses (see e.g., Jefferson, 1980; Brown & Levinson, 1987/1978), to delay or resist trouble (Jefferson, 1980; Heritage, 1998), or to mitigate a face-threatening act (Brown & Levinson, 1987/1978). However, various studies into discourse markers have also shown that delay before a reply may be related to the fact that the question may not be one-dimensional, may therefore be difficult to answer and that formulating a response requires some thought (e.g., Button & Casey, 1984; Coupland et al., 1994; Mazeland, 2016). Taking this into consideration, it is likely that the difficult choices patients need to make in formulating the answer to their doctor's 'How are you?' question are reflected in the heavy use of delay; it shows that the answers require some thought, are 'searched for' (Button & Casey, 1984, p. 177) and may be complicated (cf. Mazeland, 2016). So, far from being phatic, automatic, social responses, the responses in the data seem to be well-considered, complex and institutionally oriented.

6.0 Summary and Discussion

Contrary to findings in much previous research on the 'How are you?' question in medical contexts that report confusion about the social or medical interpretation of the question (see e.g., Coupland et al., 1994; Frankel, 1984; Rogers & Todd, 2010), the 'How are you?' question opening the consultations in this study was consistently interpreted as a medical inquiry. Patients constructed the question as a first concern elicitor that makes a response relevant that refers to the medical condition of the patient (cf. also Gafaranga & Britten, 2005; Heath, 1981).

A number of dimensions of the global and local contextual parameters of the specific encounter were identified that may account for these findings. First, the wider socio-cultural context might influence the interpretation of the question. Dutch routine procedures create affordances for three of the four tasks that establish the medical context to be completed before doctor and patient enter the consultation room (greeting, establishing identity and checking records; Robinson, 2013). The fourth task, embodying readiness is realised by means of a wide range of other contextualisation cues that the physicians use to effectuate and facilitate the transition from social to medical context, such as discourse markers, gaze, reading patients' files, etc. (cf. e.g., Coupland et al., 1994, Heath, 1981; Robinson, 2013), which afford a medical interpretation of 'How are you?' questions (Heritage & Robinson, 2006b; Robinson, 2013).

Also, much of the earlier research does not seem to differentiate between different types of consultations in their analysis of 'How are you?' openings (e.g., Coupland et al., 1994; Frankel, 1995; Rogers & Todd, 2010). It can be argued, however, that such differentiation is relevant to the interpretation of the question (see also Heath, 1981; Gafaranga & Britten, 2005). The fact that the follow-up cancer consultation is, by definition, a return visit is consequential for the interpretation of the question. Doctors topicalised this feature of the consultations in the data using a *temporal addendum*, such as 'since your last visit'. Also, since – in contrast to e.g., acute GP consultations – in return visits doctor is familiar with the complaints that have brought the patient to the consultation room, patients tend to interpret 'How are you?' questions as designed to refer to this knowledge and as soliciting a medical reply that is relevant to patient's illness' (Heath, 1981). Heath (1981) and

Gafaranga & Britten (2005) analyse 'How are you?' as a typical way to elicit medical information from patients in return consultations.

Finally, the findings indicate that research into the interpretation of 'How are you?' questions should include an analysis of the nature of the patient group that the data focus on. For cancer patients (and also for other groups of patients, such as e.g., those with chronic conditions, or geriatric patients, cf. Coupland et al., 1992) 'How are you?' is a complex question to respond to. This complexity shows in the pervasive and sometimes heavy use of delay at the start of response turns and in the often seeming contradiction between a positive first gloss and the expression of complaints, either in same turn or later in the consultation.

7.0 Conclusions

In order to understand what happens in the openings of medical consultations and to account for differences in patient interpretation of the 'How are you?' question, the analysis benefits from a context-sensitive approach, in combination with the analysis of the question-response adjacency pair, which

- zooms out and scrutinises global, institutional contextual parameters of the speech event, taking into account the importance of the inclusion of multimodal data;
- zooms in to the local interactional parameters of the speech event as they surface in the formulation of the question and the (possibly) inherent complexity of the answer for the particular patient group under investigation.

Chapter 4: The ‘Key’ of the follow-up cancer consultation

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1.0 Introduction

Previous research has suggested that most physician-patient communication in cancer consultations includes elements of an orientation towards wellness, hope and optimism (see e.g., Beach, 2013; Beach, 2014; Gutzmer & Beach, 2015; Jarret & Payne, 2000; Leydon, 2008), which would give the consultations a positive ‘Key’ (Hymes, 1977) or tone. As Beach (2014) put it, “few other medical settings are more ‘benign’ than interactions designed to manage ‘malignancies’ during oncology encounters” (p. 459). Instances of orientations to wellness, hope and optimism have been documented in a wide range of oncological encounters, and have been seen to be discursively co-constructed by patient and health-care staff (see e.g., Beach, 2013; Beach, 2014; Gutzmer & Beach, 2015; Jarret & Payne, 2000; Leydon, 2008).

Many of the studies mentioned above focus on an undifferentiated patient group, combining data from different types of consultation with patients with various types and stages of cancer.[25] This chapter aims to refine the discussion of the Key of the cancer consultation by focussing exclusively on the *follow-up head-and-neck cancer consultation,* i.e. on one type of consultation and one type of cancer. The follow-up cancer consultation is a very specific type of consultation in that it deals with “a distinct phase on the cancer control continuum”, i.e. “the period of health and wellbeing experienced by survivors after active cancer treatment (and before diagnosis of recurrence or a new malignancy)” (Rowland et al., 2006, p. 5101). Since patients do not necessarily have a problem to present, it has a different goal orientation from other types of consultations. The aims of the follow-up cancer consultation include monitoring the patient for signs of recurrence, metastasis and second primary

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[25] An exception to this is Sandén et al. (2001), which focusses on follow-up consultations with patients with testicular cancer.

tumours, monitoring the (management of) – sometimes severe – after-effects of the malignity and its treatment, including quality of life, and reassuring patients and relieving anxiety (see Chapter 2; Chapter 5; National Cancer Institute, 2010).

A possible orientation towards wellness in doctor-patient interaction during follow-up cancer consultation may be expected for a number of reasons. The first is a commonsensical one: wellness is what treatment is aiming for. The follow-up trajectory is the period after the treatment and – hopefully – the eradication of the malignancy, which should, ideally, lead to the recovery of the patient; i.e. to the patient regaining the state of 'wellness' as in 'absence of illness'. This is linked to the fact that during the routine follow-up consultation the chance of finding recurrence is small, especially when patients have no symptoms (see e.g., De Visscher & Manni, 1994, Ritoe et al., 2004).[26] Recurrences are found mostly at *unscheduled* appointments made at the request of patients who are experiencing worrying symptoms. This is shown, e.g., in Kothari et al. (2011), who followed 1,039 head-and-neck cancer patients in the UK, and found that suspicion of recurrence was noted in "68% (n = 60/88) for the subset of patients who requested an appointment"; "suspicion of recurrence was noted in 10% (n = 96/951) of patients seen routinely"; and "only 0.3% (n =3/1,039) of asymptomatic patients attending routine appointments were suspected of having a recurrence" (p. 1191). In line with these findings, then, the default expectation during the routine follow-up consultation is that the patient is likely to be doing well in terms of absence of recurrence.

The second reason (on another level) why an orientation to wellness is expected is the increased urgency at this stage of the cancer trajectory of the societal obligation for every patient to move out of the 'sick role' (Heritage & Maynard, 2006b; Parsons, 1951; Pilnick & Dingwall, 2011) and – as far as possible – move back into the role that he or she occupied in society before the onset of cancer. Parsons (1951) argued that sickness is a temporary[27] 'aberration' from the norm, incapacitating patients so that they are prevented

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[26] Ritoe et al. (2004) have shown that in only 2% of the follow-up visits of patients treated for laryngeal cancer a recurrence or second primary was found. Similarly, in a study of patients with squamous cell carcinoma of the larynx, pharynx, and oral cavity, De Visscher & Manni (1994) found: "The detection rate for events during routine follow-up (6350 appointments) was one in 34, and for self-referrals (54) it was one in 2.7" (p. 934).

[27] In his 1975 article Parsons includes a discussion of chronic illness, which needs to be *managed*, rather than cured (p. 262).

from performing their role in society, or, as he formulated it later, “an impairment of the sick person's integration in solidary relationships with others, in family, job, and many other contexts” (Parsons 1975, p. 260). To overcome their sickness, patients are entitled to medical help, suspension from their duties in society, and support from those around them. They are, however, also expected “to want to ‘get well’ [… and] to *cooperate* with [the physician] in the process of trying to get well” (Parsons 1951, p. 437). In this reintegrative recovery process, the physician – who is imbued with the authority[28] and expertise to give medical help – is both the helpmeet of the patient and the gatekeeper to their status of being ill. Patient and physician, then, are expected to collaborate in the task of moving the patient out of the sick role, into a return to their ‘normal’ duties.[29] Although this structural-functionalist take on health and sickness has been much criticised, its basic tenets are still relevant today (Pilnick & Dingwall, 2011). Doctors and patients are seen as together (re-)creating and conforming to the domination of the norm (Williams, 2005).

A third, perhaps counter-intuitive reason why the follow-up consultation is a likely place to find an orientation towards wellness is the fact that cancer survivorship is attended by what McKinley (2000) terms “the immeasurable uncertainty of survivorship” (p. 480), which is fraught with a range of anxieties and uncertainties, chief of which is the constant fear of “recurrence, other cancers, late effects of treatment, and the potential of a shortened life expectancy” (Deimling et al., 2006, p. 306). As one cancer survivor put it: “The one good thing about *having* cancer was that I did not need to be afraid of *getting* cancer” (personal communication). This leads Sandén et al. (2001) to propose that “in follow-up cancer consultations 'fears’ are potentially always there as a horizon for thoughts about the future. A major objective for the patients could therefore be assumed to be reassurance that ‘things are okay’” (p. 140). Beach (2013) argues that this anxiety and the need to relieve it may

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[28] Patient agency, improved lay knowledge and shared decision making notwithstanding, the doctor-patient relationship, sixty years on, is still asymmetrical, involving as it does doctors’ technical expertise and authority in medicine based on many years of study and experience (Parsons, 1951 and 1975; Pilnick & Dingwall, 2011; Prior, 2003; Williams, 2005; but see also Chapter 7).

[29] A large proportion of head-and-neck cancer patients does indeed return to work. In fact, a study following 264 Irish head-and-neck cancer survivors found that “[t]wo hundred three individuals (77%) reported taking time off work following their HNC diagnosis, with 119 of these individuals (59%) reporting that they had since returned to work” (Pearce et al., 2015, p. 32). However, this figure goes down with the size of the tumour and the invasiveness of treatment: only around 50% of patients who have undergone laryngectomy return to work (Costa et al., 2018; Hirani et al., 2015).

lead to an orientation towards wellness: in order to ward off the possibility of a recurrence of cancer, patients may try to 'talk wellness into being' by orienting towards wellness, e.g., by minimising symptoms.

Finally, an orientation towards wellness may also function as a coping mechanism, intended to keep up hope in a difficult situation. Groopman (2004) emphasises the importance of hope in coping with illness and states that hope is nearly always possible because "each disease is uncertain in its outcome, and within that uncertainty, we find real hope, because the tumour has not always read the textbook, and a treatment can have an unexpectedly dramatic impact" (p. 210). According to Beach (2014), "being hopeful can be a steadfast resource for simply moving forward and managing health circumstances as best possible" (p. 472), while Jones (1997) proposes that positive assessments "offer encouragement and support and highlight the sometimes hard-to-come-by good news in situations involving serious health problems" (p. 123). In situations where little can be done for patients beyond reassuring them, providing hope is the one form of medical problem-solving doctors are still able to perform. This is not just the case in advanced or chronic cancer but also in the essentially indefinite period of cancer survivorship, in which the disease could resurface at any time.

The follow-up cancer consultation then seems a likely place for an orientation to wellness. At the same time, however, cancer patients involved in follow-up often suffer from a variety of after-effects of the malignancy and its treatment. This is especially true for head-and-neck cancer survivors, who may suffer from particularly debilitating after-effects, such as disfigurement due to the removal of an eye, or ear; lack of mucus leading to problems with swallowing and eating; communication problems after the removal of the voice box or (part of) the tongue, and thyroid problems resulting from radiation therapy, which may lead to continuous tiredness. The severity of these remaining problems may lead patients to remain in the patient role for longer than most cancer survivors. Also, as a result of this, head-and-neck cancer survivors on average show higher levels of distress than other cancer patients (Gil et al., 2012). All this might very well surface during the follow-up consultations.

In the light of the above it is hypothesised that the head-and-neck cancer follow-up consultation has a *hybrid* focus: on the one hand there is reason to expect a pervasive orientation to wellness, on the other hand patients may suffer from a catalogue of distress that might well lead to an orientation to perceived problems. The aim of the current study is, therefore, to gain a more precise understanding of the ways in which doctors and patients negotiate the complex nature of the follow-up consultation and its relation to the Key of the interaction. The data for this study comprise the interactional data from 28 standard follow-up consultations, conducted by four oncologists at the head-and-neck cancer centre of the NKI (Control group); patients’ medical data; and patients’ filled out DT+PLs (see Chapter 1).

2.0 Orientation towards wellness and problems in the cancer-care trajectory: Previous research

Wellness orientation by both caregivers and patients, in consultations with patients with different types of cancer, in different stages of the ‘cancer trajectory’, has been reported on in a number of ethnomethodological and conversation analytical studies.

Beach (2013) shows that some patients who had been referred to a cancer clinic by their GPs – so in the very early stages of the cancer trajectory – were *justifying their wellness* rather than claiming illness, trying to “ward off and mitigate the threats of cancer” (p. 578) in “attempts to talk health and healing into being” (p. 579). Jarrett & Payne (2000) report how, during treatment, nurses and patients together construct interactions of an optimistic nature, during which “the atmosphere could be construed as constructive, but realistic” (p. 83). Like Beach (2013) they found that “‘minimising’ or ‘reframing’ negative issues or comments” is one of the methods used to build this positive atmosphere, next to dwelling on “optimistic and positive aspects of the situation [and] the employment of optimistic knowledge” (p. 83). Jarret & Payne (2000) note patients and nurses seemed to agree that “dwelling on negative aspects and being pessimistic was unhelpful and detrimental to the patient’s recovery” (p. 89).

Focussing on care-givers, Leydon (2008) reports how oncologists, “when delivering bad or uncertain information” overwhelmingly used a *pairing* of bad information with better information, where the second, positive, paired part “appears to soften or mitigate [the bad or uncertain information of] the first part”; thus, “the doctor moves from *bad and uncertain* news […] to *good*” (p. 1083). The ordering is relevant here, because of what Leydon calls the “power of proximateness” (p. 1084): the patient will tend to react to the last element in the utterance “to maintain conversational coherence” (Jones, 1997, p. 136). If you end with the bad, “the bad news […] becomes salient in turn-taking terms and this can have the effect of inhibiting optimism and making it tricky to move on from the relatively bad news which is left 'exposed' at the turn ending" (Leydon, 2008, p. 1084). If the good follows the bad, this enhances "the chance that a patient will orient to the good information and in turn help to construct an optimistic interactional environment" (Leydon, 2008, p. 1084). This, Leydon surmises – similarly to Jarret & Payne (2000) – helps oncologists to walk the tightrope between being honest and factual about the uncertainties of treatment and giving the patient enough hope to be willing and able to undergo treatment and adhere to it. Other ways in which caregivers orient towards wellness include doctors referring to patients' lingering physical complaints as 'normal' to relay to patients they are still well (Gutzmer & Beach, 2015); using 'encouraging assessments' (Jones, 1997), e.g., as a reaction to patients reporting positive developments in their recovery from or dealing with cancer; and explicitly interpreting test results as 'good news' (Beach, 2014) – for example "your platelet count is normal, your ITs were normal. So, you know they all really look very good" (Gutzmer & Beach, 2015, p. 15).

All the studies discussed above show a pervasive orientation to wellness in consultations at all stages of the cancer trajectory. Doctors and patients use a wide variety of interactional moves and strategies to talk this orientation into being. This does not mean, however, that problem orientation is completely absent. Beach (2013), for instance, found that – apart from the widespread orientation towards wellness they describe – patients also expressed fears and disclosed a wide range of problems: "Justifying and legitimising wellness are as normal as establishing doctorable reasons for medical visitations" (p. 589). Beach & Dozier (2015) discuss how new cancer patients, visiting their oncologist for the first time, pro-actively nominated not only their hopes but also their fears and uncertainties. And Robinson (2006) shows that in return visits – which is essentially what follow-up cancer consultations are – doctors tend to orient towards the problems they know about from patients' previous visits, and ask patients for an evaluation, update or assessment of these concerns.

The analysis below aims to show if and if so, how these findings resonate in the follow-up head-and-neck cancer consultations in the data and how orientations to wellness and to problems are negotiated in the doctor-patient interactions during the consultations.

3.0 Results

3.1 Orientation to wellness

A first, quantitative analysis of the corpus of 28 standard follow-up head-and-neck cancer consultations, with four doctors and 28 different patients, shows a clear pattern: there were instances of an orientation to various aspects of wellness in all the 28 consultations in all the stages of the encounter – during the opening of the consultation, during anamnesis, during the physical examination, and during the rounding off (cf. ‘Act sequence’, Hymes, 1977; see Chapter 2) – co-constructed by both patient and physician in multiple ways. The data below will illustrate how doctor and patient discursively construct some of these wellness orientations during the consultation.

Data 1 shows a strong orientation towards wellness at the start of anamnesis.[30]

Data 1
Dr B

[Patient had a laser excision for a glottic laryngeal carcinoma six years before this consultation, and radiation treatment for severe dysplasia of the vocal cords two years before this consultation. He has been in complete remission since then; no symptoms. DT filled out after consultation: 0/10, indicating no distress. Did not mark any of the problems in the PL]

P1	Dr: how are you doing↑	hoe gaat het met u↑
P2	Pt: fine yes absolutely no complaints anymore=	goed ja helemaal geen last verder=
P3	Dr: =no complaints experienced nothing out of the ordinary↑	=geen last geen bijzonderheden meegemaakt↑
P4	Pt: ((shakes head no, considering)) actually not no ((looks at Cp))	((schudt nee, nadenkend)) eigenlijk niet nee (((kijkt naar Cp))
P5	Dr: [((shakes head and looks at Cp))	[((schudt hoofd en kijkt naar Cp))
P6	Cp: [((shakes head)) no	[((schudt hoofd)) nee
P7	Pt: [not with my voice and with eh=	[met me stem niet en met eh=

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[30] This data is an elaborated version of Data 2, Chapter 2, which was used to illustrate how over time patients can become ‘expert’ patients in cancer follow-up.

P8	Dr: =voice is still OK ((nodding yes))	=stem blijft goed ((ja-knikkend))
P9	Pt: yes [°voice is still OK°	ja [°stem blijft goed°
P10	Cp: [((nods))	[((knikt))
P11	Dr: [eating and drinking's going well ((nodding yes))	[eten en drinken gaat goed ((ja knikkend))
P12	Pt: >eating and drinking's going well<	>eten en drinken gaat goed<
P13	Dr: ((nods yes))	((knikt ja))
P14	Pt: so eh - yes (.) actually (.) perfect	dus eh - ja (.) eigenlijk (.) perfect
P15	Dr: great (.)	prima (.)

In P1, doctor opens anamnesis with a 'How are you?' (HAY?) question. This is the standard opening in the corpus (see Chapter 3), and typical for the return visit, which is what a follow-up cancer consultation in essence is. As is typical of medical questions, it establishes both a 'topical agenda', and an 'action agenda' (Boyd & Heritage, 2006), i.e. it establishes the topic on the agenda at this moment – here, patient's state of being – and it solicits a particular action on the part of patient – here, an assessment of their own condition. The open HAY? question has no explicit orientation towards either problems or wellness and gives patients the possibility to report both positive and negative health outcomes. In the data patients respond to doctors' standard opening HAY? question with a first orientation towards overall wellness in 88.9% of cases (see Chapter 3).

Patient here reacts with an unequivocally positive assessment of his condition (P2) with the response 'fine', immediately followed by a confirmation ('yes'), and a no-problem claim using 'extreme language' (Beach, 2013; Pomerantz, 1986) to upgrade the assessment, 'absolutely no complaints anymore'. Doctor acknowledges this strongly wellness-oriented self-assessment of patient by latching on with an echo of the final part of the response, 'no complaints'. She then continues in the wellness vein with 'experienced nothing out of the ordinary', a question formulated as an elliptic phrase with flat statement intonation.

The use of 'nothing' gives the question negative polarity (Boyd & Heritage, 2006), making it a 'no-problem' or 'optimised' question, i.e. a question which embodies “presuppositions and preferences that favour ‘best-case’ or ‘no-problem’ responses” (Boyd & Heritage, 2006, p. 164; see also Beach, 2013).

Through her formulation of the question, doctor sets up the expectation that patient will confirm that he has not experienced anything out of the ordinary, the ‘ordinary’ being an absence of complaints or a continuation of known complaints. The framing of the question strongly limits the range of ‘mentionables’ (Schegloff & Sacks, 1984/1973) for the interaction. It would be ‘marked’ behaviour (i.e. an unusual discursive gambit; Scollon et al., 2012) for the patient to offer as a next topic an ‘ordinary’ experience, e.g., an unaltered chronic condition.

Since the question is in essence a yes/no question, the preferred answer, showing ‘type-conformity’ (Raymond, 2003: p. 946), would be a simple yes or no. Patient, however, shaking his head in a thoughtful manner, gives a slightly expanded reply, ‘actually, not – no’: a repeated negative preceded by a qualifier, which might indicate some uncertainty. Patient then looks at his companion for confirmation. This shift in gaze can be seen as a contextualisation cue that signals a change in the alignment of speaker and hearers (‘footing’; Goffman, 1979) and functions as a nonverbal turn allocation: companion is explicitly invited by patient to take a turn at talk. Doctor acknowledges the change in footing by also shifting her gaze to companion. Companion accepts the invitation and seconds patient’s claim to wellness with a verbal ‘no’ and a shake of her head.

Patient immediately continues with an elaboration that seems intended as the start of a list, checking off what could have gone wrong but did not: ‘not with my voice nor with eh’. Apparently, patient – who after six years of follow-up can be considered an experienced, and so ‘expert’ patient (see Chapter 2) – is aware of the tell-tale symptoms of head-and-neck cancer, and he uses this knowledge to claim that he is well, because he does not have these symptoms. This echoes the findings in Beach (2013) that “patients invoke and claim epistemic knowledge” to justify their wellness (p. 579).
Doctor continues to co-construct patient’s orientation to wellness by immediately echoing the essence of his response in an even more positive formulation (‘voice is still OK’) while nodding. Patient confirms this (‘yes’) and softly repeats ‘voice is still OK’, while companion nods. In overlap with this response, doctor asks another optimised question, ‘eating and drinking’s going well’, while again nodding ‘yes’, a question designed to, once again, elicit a positive health outcome. Patient answers affirmatively with a fast repetition of

doctor’s utterance, ‘>eating and drinking’s going well<’. Patient then initiates topic closure using the discourse marker ‘so’ (Dutch *dus* functions – among other things – as an end-of-segment marker; Redeker, 2006), followed by a summary of the findings of the preceding Q&A, which confirms his original self-assessment: ‘so eh – yes (.) actually perfect’. He uses ‘actually’ to mark a conclusion, and again uses extreme language to claim wellness. Doctor closes off this discussion with an assessment: ‘↑great’.

What seems to have been established in this segment is the co-construction – by physician, patient and companion – of wellness in the sense that patient has not presented any symptoms that indicate new or returning malignancies, which can be considered the primary wellness for a follow-up consultation. The participants have used a wide range of interactional tools to achieve this. Patient has anchored his positive self-assessment in the epistemic knowledge of the symptoms of head-and-neck cancer that he has garnered as an expert patient. Patient’s self-assessment matches the no-problem indications in his filled-out DT+PL (0 on the DT, no problems crossed on the PL).

The next data, which also occurs at the start of anamnesis, shows another strong orientation towards wellness. We enter the data just after doctor, patient and companion together have established when exactly the radiation treatment patient received was finished.

Data 2
Dr C

[Patient is a 72-year-old man diagnosed the year before first with dysplasia of the vocal cords and then with glottic laryngeal carcinoma. Received radiation therapy four months before this consultation. DT filled out before the consultation: 0/10, indicating no distress. Has not marked any of the problems in the PL]

P1	Dr:	((Dr looks at screen)) how are you doing at the moment↓	((arts kijkt naar scherm)) hoe gaat het op dit moment↓
P2	Pt:	well I mustn’t ↑grumble	nou ik mag niet ↑mopperen
P3	Dr:	is it going better and better↑	gaat het steeds beter↑
P4	Pt:	yes	ja
P5	Dr:	because that is the	dat is namelijk de [be↑doeling

		[i↑dea [((Dr makes eye contact))	[((arts maakt oogcontact))
P6	Pt:	yes yes hhh ((Dr turns back to screen)) I just have a (.) little phlegm now and then	ja ja hhh ((arts draait weer naar scherm)) ik heb alleen een (.) beetje slijm af en toe
P7	Dr:	yes ((Dr makes quick eye contact then eyes back to screen))	ja ((arts snel even oogcontact dan weer blik op scherm))
P8	Pt:	but that is °eh°=	maar dat is °eh°=
P9	Dr:	=but that is something that eh:: (.) that you do see improving in the course of time you know↑ ((looks at screen))	=maar dat is iets wat eh:: (.) wat je in de loop van de tijd wel ziet verbeteren hoor↑ ((kijkt naar scherm))
P10	Pt:	[yes yes yes	[ja ja ja
P11	Cp:	[((nods))	[((knikt))
P12	Dr:	is the voice also getting better↑	is de stem ook aan het verbeteren↑
P13	Pt:	yes(.) loads	ja(.) stukken
P14	Cp:	((looks at Pt)) it is back to ↑normal isn’t it↑	((kijkt naar Pt)) die is weer nor↑maal hè↑
P15	Pt:	almost yes	bijna ja
P16	Dr:	is it better than before↑ ((turns away from screen and starts to type, looking at keyboard)) (.)	is ‘ie beter dan voorheen↑ ((kijkt weg van scherm en begint te typen kijkend naar keyboard)) (.)
P17	Pt:	yes better [than] before I e:h	ja beter [dan] voor(dat) ik e:h
P18	Cp:	[yes]	[ja]
P19	Pt:	was ↓treated yes	ge↓holpen ben ja

Doctor looks at the screen of his computer[31] and then opens the consultation proper by asking an open HAY? question, phrased specifically as an update question 'how are you doing at the moment↓' (Chapter 3; Robinson, 2006). Patient answers with a hedge, 'well', and a fairly stoic 'I mustn't ↑grumble'. The intonation contour is upward in 'grumble', which leaves open the possibility of a fairly positive intent. Doctor apparently interprets patient's reply as less than purely positive and, resisting possible 'troubles talk' (i.e. recounting of problems; Jefferson, 1988), follows up with a second HAY? question that is very strongly oriented towards wellness: 'is it going better and better↑'. This question is formulated as a yes/no question with a positive polarity, i.e. designed to elicit the answer 'yes', a 'no-trouble' response (see e.g., Stivers & Heritage, 2001). Like the 'no complaints' question in Data 1, it is an optimised question, which indicates to patient that a positive health outcome is what doctor expects to hear. The construction and the strong wording of the question make disagreement 'dispreferred' (Pomerantz, 1984) in this sense. Patient goes for the preferred option, both in terms of construction ('type-conforming', Raymond, 2003) and intent ('design-based preference', matching the preference for a positive answer, Schegloff, 2007), and responds with an unequivocal 'yes'.

Doctor then elaborates on his second question by adding an account, 'because that is the i↑dea',[32] emphasising the statement with eye contact and raised intonation at the end of the utterance. As in a number of other examples in the consultations in the data, doctor here refers explicitly to the expectation of the follow-up consultation that patient is (established to be) doing better. Patient agrees that this is the idea 'yes yes', after which doctor returns his gaze to the screen. Having established overall wellness (or at least the fact that patient is doing better than before), patient now seems to feel free to mention a problem, but he does this with a lot of mitigation, showing awareness that wellness is the norm (which he just helped to co-construct): 'I just have a (.) little <u>phlegm</u> now and then', with 'just', 'a little' and 'now and then' all working towards down-playing, minimising the symptoms. Patient thus simultaneously orients towards a problem and towards wellness: he performs both a 'troubles-telling' (he

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[31] There is little eye contact between patient and doctor because the doctor mostly looks at the screen of his computer. At the time of the recording, the hospital had just migrated to a digital records system, and most of the doctors are still very much getting used to the new situation, having to divide their attention between the patient and the screen. The data show frequent instances of doctors mentioning this transition and grumbling that they cannot type.

[32] Idiomatically: that's what we're all ↑aiming for

discusses his problems) and ‘troubles resistance’ (he minimises his problems) (see Jefferson, 1988), indicating that his symptoms do not take away from the overall wellness that has just been established. Patient continues to minimise his symptoms with ‘but that is eh’. Doctor immediately responds to patient’s concern, echoing patient with ‘but that is something that’ and further contributes to the minimising of the symptom: he formulates a ‘no-problem’ response, stating that this is a symptom ‘that you do see improving in the course of time you know’, a generic biometrical response (Beach & Dozier, 2015) invoking a positive health outcome that ‘normally’ happens. Patient answers with a ‘multiple saying’, ‘yes yes yes’, indicating that he is already aware of what doctor is explaining (see Stivers, 2004). Companion simultaneously confirms this with a small nod.

The discursive construction of wellness continues with another question by doctor: ‘is the voice also getting better↑’. The use of ‘also’ shows that doctor – responding to patient’s ‘yes’ rather than to patient’s tentative announcement of ‘trouble’ in the form of phlegm – interprets patient’s preceding utterances as conveying an orientation to improved wellness. Doctor’s question is wellness-oriented: an optimised question, strongly geared towards a ‘no-problem’ answer (Boyd & Heritage, 2006). Patient responds to this yes/no question with the preferred ‘<u>yes</u>’ (again conforming to both type and design-based preference) and then expands his answer with extreme language, ‘<u>loads</u>’, to justify his wellness (Beach, 2013; Pomerantz, 1986). Companion adds her contribution to the wellness construction with ‘it is back to ↑normal isn’t it↑’, to which patient partially agrees, with some mitigation, ‘almost yes’. Doctor needs more precise information here, asking, ‘is it better than before↑’, to which companion agrees and to which patient responds – even more precisely – ‘yes better than before I e:h was ↓treated yes’.

In this data, doctor takes a strong lead in constructing the orientation towards wellness, which is then matched by patient and companion. Patient shares his knowledge of his symptom, which doctor places in the context of ‘normal’ development, which both patient and companion accept as expected (‘yes yes yes’). Together, doctor, patient and companion discursively construct an orientation towards wellness, in the sense of symptoms and after-effects improving as-per-normal, in accordance with the aim of the follow-up trajectory.

Data 3 shows wellness-orientation during the physical examination, which routinely follows anamnesis. Dr C is checking patient’s neck in the final stages of the physical examination.[33] Doctor comments immediately on what he has seen (Heritage & Stivers, 1999), which is what all doctors in the data do while performing the physical examination.

Data 3
Dr C

P1	Dr:	could you stick out your tongue (.) and could you say EEEEEEEEEEEE	steek de tong eens uit (.)en zeg eens IEIEIEIEIEIE
P2	Pt:	=EEEEEEEEEEEE	=IEIEIEIEIEIE
P3	Dr:	you can stop now excellent (1.2)	stop maar keurig (1,2)
P4	Pt:	[yes↑]	[ja↑]
P5	Dr:	[d]don’t see any (.) strange things↑	[ss]zie geen (.) gekke dingen↑

In P1-2 doctor is examining patient's neck to check for any abnormalities and instructs patient to make a sound while he is looking inside her mouth. On finishing the examination, he tells patient to stop making the sound and immediately assesses the condition of the neck area that had been affected by cancer with an emphatic ‘excellent’ (see e.g., Heritage & Stivers, 1999). After a short pause, patient says ‘yes’↑ with a questioning intonation, inviting doctor to reconfirm the positive verdict he has just given. Overlapping with patient’s question, doctor adds that he does not ‘see any (.) strange things’, invoking normality – absence of strange things – as positive (see Gutzmer & Beach, 2015) and thus establishing basic wellness: patient does not show any symptoms of head-and-neck cancer at the moment. Positive news and wellness orientation here go hand in hand.

Data 4 shows how doctor and patient co-construct an orientation towards wellness during the rounding off phase of the consultation, after the physical examination has been completed, and patient’s current status as cancer-free has been established.

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[33] For privacy reasons, both doctor and patient are out of shot during the physical, so there is no information on body language or gaze.

Data 4

Dr. B

[Patient was treated four months before this consultation with chemo-radiation therapy for a tonsil carcinoma. Clean since then. DT filled out after the consultation. Did not indicate overall distress level, but marked 11 of the possible 47 problems in the PL]

P1		((Dr has just completed the physical examination)	((Dr heeft net lichamelijk onderzoek afgerond))
P2	Dr:	excellent↓	prima↓
P3		((Dr and Pt move back to Dr’s desk))	((Dr en Pt gaan weer aan bureau zitten))
P4	Dr:	((looks at computer screen and types))	((kijkt naar computerscherm en typt))
P5	Pt:	((while sitting down)) so for the time being I am clean↑	((terwijl hij gaat zitten)) dus voorlopig ben ik schoon↑
P6	Dr:	((turns to patient)) yes↓	((draait naar patiënt)) ja↓
P7	Pt:	okay then we’re going to keep it that way cause I quit smo I don’t smoke anymore right	oké dan gaan we het zo houden want ik ben gestopt mè ik rook niet meer hè
P8	Dr:	((gives a thumbs up)) very good	((steekt duim omhoog)) heel goed
P9	Pt:	because for six months I haven’t smoked=	want zes maanden heb ik niet meer gerookt=
P10	Dr:	=no yes keep it up=	=nee ja volhouden=
P11	Pt:	=and (.) ((shakes head))	=en (.) ((schudt hoofd))
P12	Dr:	[don’t start again	[niet weer beginnen
P13	Pt:	[I-I am not going to smoke again ((smiles))	[i-ik ga niet meer roken ((glimlacht))
P14	Dr:	((smiling)) ↑very good ↑very good	((glimlachend)) ↑heel goed ↑heel goed

Doctor has just completed her physical examination of patient and has found nothing wrong, which she glosses with an emphatic positive assessment ‘excellent↓’ (see Heritage & Stivers, 1999). Doctor and patient move from the examination chair back to doctor’s desk and doctor proceeds to type up patient’s computer file. In reaction to doctor’s positive assessment, patient says, while sitting himself down, ‘so for the time being I am clean↑’, both asking for confirmation of this assessment, and simultaneously claiming the core wellness of not having cancer. He also expresses his awareness that this situation is not guaranteed to continue, expressed in ‘for the time being’. Doctor, turning to look at him, confirms patient’s interpretation of her assessment with an emphatic ‘yes’. Patient accepts this confirmation with ‘okay’ and then announces his intention of extending the duration of ‘for the time being’ and to contribute to his continued wellness: ‘then we’re going to keep it that way’. The formulation is very strong: ‘we’re going to’ indicates determination and fixedness of purpose, and the combination with ‘keep it that way’ signals a conviction that he has agency in this, is able to influence events and intends to do so. He then provides the reason for his conviction (‘cause’) which is at the same time the way in which he will influence events: he has given up smoking. This implies that patient is aware of the fact that smoking is a major risk factor for head-and-neck cancer, and that smoking after treatment creates a higher risk of further disease (see e.g., Gritz et al., 1993; Marron et al., 2010). Giving up smoking is therefore an important and appropriate change in lifestyle.

Patient starts his utterance in terms of ‘having given up’ smoking – ‘cause I quit smo’ – but amends this halfway the sentence to a stronger, ‘extreme case’ formulation (Pomerantz, 1986): ‘I don’t smoke anymore right’, which indicates that he now sees himself as having completed the quitting, and as now being an ex-smoker. Dutch *hè* – here translated as ‘right’ – is used to interact with the hearer, inviting hearer to respond with an acknowledgment or confirmation (Kirsner, 2003). Doctor complies, and – clearly pleased – in response praises him verbally and non-verbally for quitting smoking: ‘very good' with a thumbs-up sign. Patient – perhaps needing more confirmation – then expands on his status as non-smoker: ‘because I haven’t smoked in six months’. By adding the duration of his cessation patient provides evidence for his commitment and determination. Doctor immediately latches on to this, and – clearly aware of the difficulty of not resuming smoking – encourages him to ‘no yes keep it up’. Patient immediately responds to doctor’s encouraging admonishment by smilingly expressing his firm intention to stay off the cigarettes, ‘=and (.) I- I am not going to smoke again’, shaking his head in emphasis. Doctor overlaps with his utterance, continuing her encouragement ‘don’t start again’, and, clearly very pleased, smiles and praises him again with a repeated, emphatic ‘↑very good ↑very good’.

In this data, doctor’s positive assessment of patient’s health at this moment in time – and so for the time being – triggers patient to reveal how he is actively working to stay healthy by not smoking. Doctor’s emphatic and empathic positive assessments of his efforts and friendly encouragement combine with patient’s expressions of commitment to stay on the right track. In this way doctor and patient together orient towards continued wellness through a healthier lifestyle: not smoking.

The data above illustrate orientations to wellness in three ‘Acts’ (Hymes, 1977) of the consultation: during anamnesis (Data 1 and 2), during the physical examination (Data 3) and after the physical, at the start of the rounding off phase (Data 4). The data also show that doctors and patients orient to various *types* of wellnesses: absence of cancer (Data 1 and 3), lessening of after-effects (Data 2), and moving towards a healthier lifestyle (Data 4).

3.2 Mixed orientation

As can be seen above, instances of wellness orientation can be widely attested in the consultations in the data. However, virtually all the data also show instances in which participants are moving between an orientation towards wellness and an orientation towards problems. Data 5 shows an orientation to wellness, but also a problem orientation referencing shared knowledge about previous problems, which is typical for the medical return visit.[34]

Data 5
Dr B

[4 years after radiotherapy and chemotherapy of carcinoma of the oropharynx. Patient filled out 2 on the DT, indicating light distress, and crossed seven items on the PL]

P1	Dr:	((looks at screen))	((kijkt naar scherm))
		hHh (0.9) ehm	hHh (0,9) ehm
		((turns to Pt))	((draait naar Pt))
		[problems in the throa:t↑	[last in de kee:l↑

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[34] Incidentally, the data also show the importance of the inclusion of multimodal data to understand what is really happening in doctor-patient interaction and to establish the orientation of the participants. The video-data show doctor formulating questions that *sound* as if they are neutral in orientation or prefer a problem-oriented answer. However, her *nonverbal* behaviour in fact indicates a no-problem orientation.

		[((shakes head no))	[((schudt hoofd nee))
P2	Pt:	[no not really [((shakes head no))	[nee hoor [((schudt hoofd nee))
P3	Dr:	[voice changed↑ [((shakes head no))	[stem veranderd↑ [((schudt hoofd nee))
P4	Pt:	no	nee
P5	Dr:	[((shakes head no)) [(0.9) eating drinking going well↑	[((schudt hoofd nee)) [(0.9) eten drinken gaat goed↑
P6	Pt:	↑yes	↑ja

We enter Data 5 early in anamnesis after patient's general wellness has been established (not in transcript). Doctor now moves to specific questions, asking after problems that might signal recurrence of the malignancy in the back of the mouth, which patient was treated for four years before. Such questions reference the shared knowledge of the return visit (Heath, 1981) and are typical for follow-up cancer consultations. Doctor's first question is preceded by some delay 'hHh (0.9) ehm' and formulated as an elliptic yes-no question 'problems in the throa:t↑', inviting a yes or no response (type-conformity; Raymond, 2003). However, doctor accompanies the question with a shaking of her head, which turns the question into a no-valenced one, an optimised question which prefers a 'no-problem' response, i.e. a positive health outcome (see Heritage, 2010). So although she verbally topicalises – and thus sets the agenda for – possible problems, her body language signals wellness orientation.

Patient, shaking his head to indicate 'no', replies with *nee hoor*, which can be glossed here as 'no not really'. *Hoor* in Dutch is a versatile tag. Apart from many other things, it can be used to express reassurance and politeness, to soften a reply (Kirsner & Deen, 1990) and to involve the hearer. As Kirsner (2003) formulates it: "Hoor functions as 'linguistic touching', a kind of linguistic pat on the shoulder or arm" (p. 63). Here it seems to function as a combination of all these things, with patient as it were reassuring doctor that there are no problems.

In P3 doctor continues her questions, with the same mixed orientation of a possibly problem-oriented formulation with wellness-oriented body language: shaking her head 'no', she asks 'voice changed↑'. Again, patient gives the preferred wellness-oriented reply: an unequivocal 'no'. In P5 doctor accepts patient’s answer by shaking her head in coordination with his negative response and then unequivocally shifts to wellness orientation with the yes-valenced ‘no-problem’ question ‘eating drinking going well↑’. Patient now responds with an unequivocal ‘yes↑’. All in all, doctor and patient have co-constructed an orientation towards wellness, as in absence of symptoms of recurrence. In the same way that prosody trumps lexical delivery (Schegloff, 1986), it seems that body language trumps verbal message, with the neutral-to-problem-oriented verbal message being overturned to clearly wellness-orientated by the accompanying body gesture.

Data 6 below also shows a mixed orientation.[35] This consultation is only a short time after treatment, and patient still experiences severe after-effects.

Data 6
Dr A

[Patient was treated for a melanoma on the head three months before, followed by two operations, including excision of the lymph nodes in the neck a month later. After the consultation he filled out the DT with 7 out of 10, indicating very strong overall distress, and marked 23 of a possible 47 problems on the PL]

P1		((Dr walks to chair [sits down and looks at Pt))	((Dr loopt naar haar stoel [gaat zitten en kijkt naar Pt))
	Dr:	[how have you been doing in the meantime↑	[hoe gaat het met u intussen↑
P2	Pt:	((looks away from Dr)) ochch ((grins))	((kijkt weg van Dr)) ochch ((grijnst))
P3	Dr:	((moves chair closer to desk) in the circumsta:nces↑ (.)	((schuift stoel aan)) naar omstandighe:den↑ (.)
P4	Pt:	[much better than the last time [((smiles; looks away))	[stuk beter dan de vorige keer [((glimlacht; kijkt weg))
P5	Cp:	[((looking at Pt) [((smiling at Dr))	[((kijkt naar Pt) [((glimlacht naar Dr))
P6	Dr:	ye:s↑	ja:↑

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[35] This data was used in Chapter 3 (Data 2) to illustrate the medical interpretation of the HAY? question.

P7	Pt:	yes↓ (turns to Dr)) (1.2) ((no longer smiling, but looking serious now)) .hh no[: it’s go]ing eh:m	ja↓ ((kijkt naar Dr)) (1,2) ((glimlacht niet meer, maar kijkt nu serieus)) .hh ne[e: ’t ga]at eh:m
P8	Dr:	[tell me]	[vertel eens]
P9	Pt:	((coughs)) (1.6) as far as this is concerned completely fine ((points at left side of head)) as far as I can tell	((kucht)) (1,6) wat dit betreft helemaal goed ((wijst naar linkerzijkant hoofd)) naar mijn idee
P10	Dr:	ye:s↑ (1.7)	ja:↑ (1,7)
P11	Pt:	.hh and fortunately this is getting better too now= ((points at neck)) =has given me a lo:t of trouble that pain and.hh	.hh en dit wordt gelukkig nu ook beter= ((wijst naar hals)) =he'k hee:l veel last van gehad van die pijn en.hh
P12	Dr:	a lot of pain↑	veel pijn↑

After settling the patient and his companion, the physician opens the consultation proper by asking patient ‘how have you been doing in the meantime↑’. As in Data 4, doctor asks an open HAY? question but limits its scope to ‘in the meantime’, i.e. to an update question related to the period after the last visit, which is typical for the return visit. Patient looks away from doctor, displaying hesitation towards answering this question, and, smilingly, hedges with ‘ochch’ (P2). Doctor seems to read this as a trouble premonitory response (Jefferson, 1980), signalling that patient might be starting a troubles-telling. Doctor now forestalls a further problem orientation and amends her question, limiting it to ‘in the circumstances↑’. The addition of ‘in the circumstances’ is particularly relevant here since patient was operated on three times in the last three months and the likelihood that patient is not feeling particularly well is strong. Also, with respect to cancer survivors, ‘How are you?’ may be interpreted within the frame of reference of having been treated for cancer, which in itself is distressful (see e.g., Beach et al., 2005; Coupland et al., 1992; Chapter 3). Doctor thus steers patient away from troubles talk relative to how he might *wish* to feel, to how he feels *relative to his circumstances*.

Patient, still smiling and looking away, responds accordingly (P4), concentrating in his answer – in response to doctor’s first formulation of the question, ‘in the meantime’ – on how his situation has changed since the last visit: ‘much better than the last time’. Patient’s smiles and looking away may be interpreted as the embodiment of the existential fear that patients suffer after a brush with cancer, even in the presence of good news; as Beach et al. (2005) state: “any ‘good news’ is situated in the midst of an extended and complicated medical history and a potentially ‘dreaded future’” (p. 898). It may also reference that he is not conveying how he might *wish* to feel but how he is feeling in the circumstances of recovering from treatment.

Patient’s companion, who was looking intently at patient when he was answering the question, seems content with this wellness-oriented gloss and confirms it by smiling at doctor. By asking ‘ye:s↑’ (P6), doctor acknowledges patient’s answer and at the same time asks him to confirm that he is sure of his wellness-oriented self-assessment. Patient responds with an emphatic confirmative ‘yes↑’ (P7), firmly establishing that he is better than the last time, so, by implication, as well as can be expected in the circumstances.

Patient now turns to doctor and looks at her seriously, no longer smiling. He then utters a number of possible trouble premonitors: a delay with ‘hh’ and a stretched out ‘no:’. This might indicate that what will follow may be a complex answer, not just conveying good news (Mazeland, 2016). Jumping in halfway patient’s ‘no:’, doctor encourages him to continue with ‘tell me’, orienting to what patient wants to share. Patient again delays his answer with a cough and a pause (P9), marking a possibly complex answer, and then first elaborates on what is going well, still adhering to the wellness orientation he and doctor have discursively achieved. He states that the two areas that are most relevant to his head-and-neck cancer history, the side of his head and his neck, are respectively ‘completely fine’ – stressing wellness with extreme language (Beach, 2013; Pomerantz, 1986) – and ‘getting better too now’, thus establishing wellness in terms of lack of dangerous symptoms, diminishing after-effects, and overall wellness ‘in the circumstances’. The way he formulates this, however, includes more trouble premonitors: ‘as far as <u>this</u> is concerned’, limiting the scope of wellness, and ‘<u>this</u> is getting better too now’, giving a temporal limitation with ‘now’– implying it was not well before –, plus a hedge ‘as far as <u>I</u> can tell’, so as far as he himself can determine. The latter leaves open the possibility that other observers (*in casu* the doctor) might disagree, and hints at the possibility of recurrence. So patient limits his wellness to these aspects, to the here and now, and to his own opinion. He then moves from wellness orientation to problem orientation and launches into a troubles-telling, relating how bad the pain in his neck has been until recently with emphatic intonation and hyperbole: '=has given me a lo:t of trouble that pain and .hh' (P11). Rather than using extreme language to establish wellness (Beach, 2013; Pomerantz, 1986), patient here uses extreme language to describe physical distress, thus creating doctorability for his distress (Heritage & Robinson, 2006a). This time, doctor does not deflect patient's troubles-telling but invites patient to elaborate with a questioning semi-repetition of patient's trouble, 'a lot of pain↑'. By echoing and thus emphasising the severity of the distress – 'a lot' –, doctor co-constructs with patient a problem orientation at this stage of the consultation. What follows (not shown here) is a discussion of the area that caused patient so much pain, ending in doctor telling patient that she will have a good look at the area during the physical examination, which she later does, and which ends in the reassurance that everything looks 'quiet' and 'normal'.

By re-orienting her question towards 'in the circumstances', doctor has discursively limited the number of mentionables as first topics of the interaction (cf. Schegloff, 1982). It seems that, as a first topic, a discussion of complaints is not in order. The first thing to establish is overall wellness – i.e. absence of cancer-related problems – in the head-and-neck area. Only when this has been achieved, is a discussion of after-effects and problems a possible next topic. This is in line with the analysis of first topics by Schegloff & Sacks (1984/1973), who state that "to make a topic a 'first topic' is to accord it a certain special status in the conversation. Thus, for example, to make a topic 'first topic' may provide for its analysability (by co-participants) as 'the reason for' the conversation" (p. 77). Apparently, the physician does not wish to accord first-topic-status to the discussion of problems. This does not mean that problems will be ignored. As can be seen in this data, they can be introduced as a topic later in the conversation. But first, the overall wellness of patient is established, which then becomes the gloss for the consultation as a whole, i.e. that patient is doing well *in the circumstances*, in relation to the improvement of after-effects of the tumour and its treatment. Only then can the after-effects that patient is suffering from be brought up, introduced by an account of improved wellness.

In Data 7 below, which occurs during and after the physical examination, doctor and patient seem to disagree on whether or not patient has a doctorable problem, i.e. a problem that warrants medical attention. We enter the data during the physical examination, with doctor informing patient that he has noticed that part of her tongue has become stuck to the bottom of the mouth, with reduced mobility of the tongue as a result.

Data 7
Dr C

[Patient has a long medical history, with various cancer episodes, including a tongue carcinoma with extensive dysplasia which was treated with superficial trans-oral excision right side floor of the mouth, split skin graft and palatal obturator; a few months before this consultation, possible metastasis in neck lymph nodes, which turned out to be a false alarm. DT filled out after the consultation: 4/10, indicating a level of distress that is considered within normal parameters. Marked two of the possible 47 problems in the PL]

P1	((Physical examination is going on. Patient is invisible in examination chair. Doctor can be seen only partly. So no possibility of observing eye contact, etc.))	((Lichamelijk onderzoek is aan de gang. Patiënt is buiten beeld in onderzoeksstoel. Doctor is gedeeltelijk in beeld. Geen mogelijkheid observeren oogcontact, etc.))
P2	Dr: well you see that tongue has anyway eh ehm (.) got stuck to to that floor of the mouth that that now limits the mobility	hè je ziet die tong is toch eh ehm (.) gaan vastzitten aan aan die mondbodem dat dat beperkt nou de beweeglijkheid
P3	Pt: yes	ja
P4	Dr: we’re not going to do anything about that for now but if this stays the same or gets worse yes then we h-have to see whether we might not one day need to take out a bit of that scar tissue	daar gaan we voorlopig niks aan doen maar als dit zo blijft of erger wordt ja dan m-moeten we kijken of we daar niet een keer een stuk van dat littekenweefsel moeten wegnemen
	Lines left out: explanation of problem and procedure	
P5	Dr: but that is another ope↑ration and .hh I can imagine that you have had enough of that for the time being	dat is wel weer een ope↑ratie en .hh ik kan me best voorstellen dat u daar even klaar mee bent
P6	Pt: yes totally	ja best wel
P7	Dr: so eh:m this is also something that you do not (.) want to do now but	dus eh:m dat is ook iets wat u niet (.) nu wil doen maar

		something that we could keep in ↑mind that if necessary it is possible if you really think that this sc-scar goes still further	dat we dat wel in ge↑dachten houden dat dat eventueel zou kunnen als u echt vindt dat dit litte-teken nog verder gaat
P8	Pt:	.hh in in itself that does not give me so much ↑trouble really that that I do-don’t think so	.hh op op zich daar heb ik niet zo heel veel ↑last van eigenlijk dat dat vind ik nie-niet
P9	Dr:	no that the point is I I think ↑personally that ↓no I last spoke with you two and a half months eh ago I I heard that the the the tongue that speech (.) is going a little bit harder [>I don’t know <	nee dat het punt is ik ik vind per↑oonlijk dat ↓nee ik heb u het laatste tweeën-halve maand eh geleden gesproken ik ik hoorde dat de de de tong dat de spraak (.) iets moeilijker gaat [>'k weet niet<
P10	Pt:	[oh no according to [me] not no	[o nee volgens [mij] niet nee
P11	Dr:	[neh]	[neh]
P12	Pt:	[.hh 't is]	[.hh 't is]
P13	Dr:	[and what does] the eh:: Mary say about it↑ °because°	[en wat zegt] de eh:: Mary daarvan↑ °want°
P14	Pt:	no she ↑also thought it was f[ine]	nee die vond het ↑ook p[rima]
P15	Dr:	[°okay°]	[°oké°]
P16	Pt:	the only thing [is that]	het enige [is dat]
P17	Dr:	[no it is] fine but I’ve got the idea that it that I can hear ↑just a little more that that tongue °so (.) (has difficulty moving)°	[nee het is] prima maar ik heb het idee dat het dat ik het ↑iets meer hoor dat die tong °zo (.) (moeilijk beweegt)°
P18	Pt:	no it is in the ↑mornings eh:: stiffer (.)	nee 't is 's↑morgens eh:: strammer (.)
P19	Dr:	((indicates Pt can return to her chair))	((wijst patient terug naar haar stoel))
P20	Pt:	in eh in the course of the	in eh in de loop van de

		day it gets ↓better (3.6)	dag wordt het ↓beter (3.6)
P21		((Pt gets off the examination chair, walks back to chair behind the desk and sits down; both now in frame; eye contact))	((Pt komt weer van de onderzoeksstoel af en loopt naar bureaustoel en gaat zitten; beiden in frame; oogcontact))
P22	Pt:	then then it is just like it ↓ye:s ehh it is a ↑muscle that has to warm ↑up ((gestures upwards with hand))	dan dan is het net alsof het ↓ja: ehh het is een ↑spier die moet ↑opwarmen ((gebaart omhoog met hand))
P23	Dr:	yes yes yes .hh now that that will also keep eh eh:m being ↑necessary that you really (.)as much as possible keep doing	ja ja ja .hh nou dat dat blijft ook eh eh:m nood↑zakelijk dat je echt (.)zo veel mogelijk blijft doen
P24	Pt:	yes	ja

During the physical examination, at the start of Data 7, doctor notices scar tissue threatening to reduce the mobility of patient’s tongue, which might need an operation at a later point in time (P2, 4, 5) if ‘this sc-scar goes still further’ (P7). He formulates this problem with some disfluency and hesitation (well, eh uhm, .hh, h-have, sc-scar), signalling the dispreferredness of communicating problems and bad news. Patient does not respond positively to this suggestion; in fact, she denies that there is a problem (P8) – ‘does not give me so much ↑trouble’ –, expressing disagreement with an assessment, which is a dispreferred action even in most ordinary conversational situations (Pomerantz, 1984), let alone in the institutional setting of a medical consultation. The dispreferredness of her response is signalled by delay in the form of turn-initial audible breathing (.hh), intra-turn disfluency (in in’; ‘that that’; ‘do- don’t’), and limiters (‘really’; ‘in itself’). By disagreeing with doctor and claiming wellness, patient contests an unwelcome problem orientation and attempts to forestall further treatment (Beach, 2013). Being familiar with patient’s long and complicated medical history, doctor already anticipated this, ‘I can imagine that you have had enough of that for the time being’ (P5). However, doctor stands his ground in his problem orientation (P9), but now he, in his turn, has to deal with the dispreferredness of disagreeing with his patient in her claim of wellness. This is marked by the heavy delay and hedging at the beginning of the turn: ‘no that the point is I I’, followed by a claim that the rationale for treatment is a personal opinion rather than a medical fact, ‘I think

↑personally that'. He then offers what Peräkylä (2006) calls "inexplicit reference to the evidence" (p. 218), "citing the sensory evidence on which [his] conclusions are based", which, according to Peräkylä "mark[s] the diagnostic statement as tentative" (p. 219). This utterance again includes much intra-utterance disfluency ('I I'; 'the the the'; 'the tongue that speech'), and emphasised mitigation ('<u>a little bit</u>'). Doctor ends his turn with a: 'I don't know', uttered very fast, seemingly indicating uncertainty about the diagnosis.

Doctor's display of tentativeness and uncertainty allows patient to challenge his diagnosis, as argued by Heath (1992): "Displaying uncertainty or tentativeness concerning the diagnosis or medical assessment can itself serve to encourage patients to respond" (p. 247). Patient's reaction is now strong and immediate: overlapping with doctor's last hedge, she utterly rejects doctor's negative assessment of her speech (P5) and strongly defends her wellness with a dismayed 'oh <u>no</u>' at increased volume. The turn contains a total of three negations of doctor's assessment: 'oh <u>no</u> according to me not no' (cf. Beach, 2013).

Patient continues, but doctor interrupts and queries what the speech therapist thinks about it, thus invoking a second opinion from another medical authority (P13): 'and what does the eh:: Mary[36] say about it↑'. This is followed by a very soft '°because°'. The question and '°because°' together give doctor a possibility to drop the issue: if the speech therapist, in her expert opinion, does not think there is a problem, he can defer to her authority and let it go.

Patient responds by again repeating that 'no', there is no problem, backing this up with the requested expert assessment, 'she ↑also thought it was fine', with the stress on 'also' emphasising their joint opinion. Doctor immediately defers to the speech therapist's judgment ('okay'), and when patient seems to want to bring up a small problem 'the only thing is that' simultaneously with that utterance, again confirms and expands this with 'no it is fine', with a flat intonation that signals he is convinced.

In the next part of his turn (P17), however, doctor returns to his original observation that patient's tongue is not as mobile as it should be. Again, it is presented tentatively, this time phrased as a personal opinion ('I've got the idea that'), with hesitation ('that it that I') and mitigation ('just a ↑little more').

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[36] Not her real name.

Patient again denies the problem (‘no’), expanding her turn to give an extensive explanation of what she thinks is the problem (a stiff muscle that has to warm up) and what she does about it, justifying her wellness by reducing doctor’s perceived medical problem to nothing more than a stiff muscle, and by using practical medical knowledge of what needs to be done about it (Beach, 2013).

Doctor is finally drawn into patient’s display of wellness, in this case of not having anything seriously wrong with her and not needing medical attention, and now responds with (‘yes yes yes’) under a single intonation contour. Stivers (2004) states that this type of ‘multiple sayings’ may be an indication that the turn it responds to “was unnecessary and should properly be halted” (269). This fits the data, since telling a doctor how to treat a stiff muscle is telling him something that he already knows; it is superfluous information and so violates the Maxim of Quantity for effective communication (Grice, 1975). Continuing his turn, doctor now – with some hesitation markers – agrees with and stresses the importance of the treatment patient has outlined for her tongue (P23), ‘.hh now that that will also keep eh eh:m being ↑necessary that you really (.) as much as possible keep doing’. In this way he falls in line with patient’s persistent orientation to wellness.

This sequence shows an unusual mix of problem and wellness orientation. Doctor notices a problem that he assesses as doctorable, which he communicates to patient with much mitigation and delay, which indicates the dispreferredness of introducing a problem. Patient strongly resists his diagnosis, contradicting doctor’s observation that there is an after-effect of the treatment that may need surgery, talking wellness into being and thus forestalling the need for further treatment. The disagreement gets resolved in a co-constructed orientation towards wellness at the end of the data.

In the mixed orientations in the data – as exemplified in the data above – we see that while patients may use strong formulations and hyperbole to detail their problems once they are on the table, the *first introduction* of these problems is always accompanied by delay, hesitation and mitigation.

There was one exception to this pattern in the corpus: this consultation shows a strong problem orientation, with patient introducing physical distress in an unmitigated fashion.

Data 8
Dr C

[18 months after excision of carcinoma in the floor of the mouth. Patient crossed 7 on the DT, indicating high distress, and filled out 13 items on the PL, four of which were emotional]

P1	Dr:	↓okay ((looking at screen)) .hhh eh:: we have known you since eh(.) already about ((turns to Pt)) two years isn’t it because of a eh tumour of the floor of the mouth .hh with originally many problems .hh with eating afterwards you were fitted with those ↑implants [((turns to screen and back to Pt)) [and ehm (.) well then you said actually that it was going much ↑better how is it at this moment↑	↓oké ((kijkend naar scherm)) .hhh eh::, wij kennen u sinds eh (.) al een jaar of ((draait naar Pt))twee hè vanwege een eh tumor van de mond- bodem .hh met oorspronkelijk veel problemen .hh van het eten nadien heeft u die implan↑taten gekregen [((kijkt naar scherm en terug naar Pt)) [en ehm (.) nou toen vertelde u eigenlijk dat het veel beter ↑ging hoe is’t op dit moment↑
P2	Pt:	>going well apart from the tongue< that is a <disa:ste:r>	>gaat goed op de tong na< dat is een <dra:ma>
P3	Dr:	because what are all the things that are happening with that tongue↑	want wat gebeurt er allemaal met die tong↑
P4	Pt:	well one moment then I have an an idea that [it’s burnt [((grabs chin)) that there [is a great big ↑blister on it [((rubs cheek))	nou de het ene moment dan heb ik een een idee dat [hij verbrand is [((grijpt naar kin)) dat er [een hele grote ↑blaar op zit [((wrijft over wang))
P5	Dr:	yes	ja
P6	Pt:	.hh the next moment then it is [↑tingling ho:rribly [((gestures)) or or s (.) I don’t know what (.)	.hh het andere moment dan is-ie [vre:selijk aan het ↑tintelen [((gebaart)) of of ze s (.) weet ik wat (.)

		there is something ↑all the time and it it really ↑hurts	er is ↑elke keer wel wat en het het doet me ook ↑zeer
P7	Dr:	yes [°and°]	ja [°en°]
P8	Pt:	[and the] ↑food has no taste either [I ↑do eat but what I eat [((gestures)) I cannot taste anything anymore and that has been for the ↑last (.) ((looks at companion; he looks back)) three weeks↑ it has been a <disa:ste:r>	[en 't] ↑eten smaakt me ook niet [ik ↑eet wel maar wat ik eet [((gebaart)) ik heb geen smaak meer en dat is sinds de ↑laatste (.) ((kijkt naar companion; hij kijkt terug)) drie weken↑ is 't een <dra:ma>
P9	Dr:	so gotten worse actually↑	dus erger geworden eigenlijk↑
P10	Pt:	=yes and I have ↑said (.) if I had ↑known this I would never have had that ↑second operation then I would just have left it at the first one	=ja ik heb ook ge↑zegd (.) als ik dit ge↑weten had had ik die ↑tweede operatie nooit gedaan dan had ik het gewoon bij de eerste gelaten

In Data 8, doctor opens the consultation by briefly summarising patients’ medical history (cf. Heath, 1981; Coupland et al., 1994). By focussing on a ‘shared history’ (Heath, 1981), he talks the medical context of the return visit into being (Heritage, 1984). After bringing to mind patient’s type of tumour and her problems with eating after treatment, he finishes off his summary with a strong orientation towards wellness, quoting patient as having said that – with the new implants – ‘it was going much ↑better’. He continues with a time-focussed HAY? question, ‘how is it at this moment↑’. Although the preceding focus on wellness may prime patient towards a wellness-oriented response, the question itself is open and – with the time focus ‘at this moment’ – leaves open the option of a change in circumstances and a problem-oriented response.

Patient’s response is, in fact, complex (Mazeland, 2016), combining both a wellness and a problem orientation. She gives a gloss of general wellness unequivocally without hedging or delay, ‘going well’, but this gloss is immediately qualified without delay or hesitation, ‘apart from the tongue’, followed by the hyperbolical ‘that is a disa:ste:r’ with markedly slower speech rate, flat emphasis and lengthening of the vowels. These prosodic contours show emotional intensity and emphasise the severity of the problem. So, in response to doctor’s ‘first concern elicitor’ (Gafaranga & Britten, 2005) ‘how is it at this moment↑’, patient has replied first by indicating general wellness and then by voicing an urgent first concern. Although such complex answers generally might be understood to indicate exactly what patients mean – i.e. on the whole I am doing OK, but I also/still suffer from x (see Chapter 3) – , in this case, given the intensity with which patient formulates her distress, the wellness orientation at the beginning of the utterance might be analysed as a *pro-forma* nod (Schegloff, 2007) to the preferred wellness orientation of the follow-up consultation, delaying the dispreferred problem orientation.

The problem is voiced *after* the good news, which – by the power of proximateness (Leydon, 2008) – makes problem orientation more salient in turn-taking terms. In line with this, doctor immediately (Beach & Dozier, 2015) continues the problem orientation, picking up on the second part of patient’s response, i.e. the problems with the tongue, and inviting patient to elaborate on the troubles she has announced. Patient does so accordingly, starting her turn with a discourse marker announcing a complex response (‘well’; Mazeland, 2016). Patient then indicates that she is starting an extended, multi-unit turn with ‘one moment’. This projects a ‘next moment’ in her account, and thus defers the possible completion of her turn till after she has filled the projected slot (Schegloff, 1982). There is no mitigation or minimising of trouble here as in the more wellness-oriented mention of a problem in e.g., Data 2, but strong emphasis on the problems, through illustrative gestures (grabbing chin and rubbing cheek), intonation (‘I have an an idea that it is burnt’; ‘it really hurts’) and hyperbole (‘that there is a great big ↑blister on it’; ‘↑tingling ho:rribly’; ‘really’). Patient uses ‘extreme case formulations’ to “legitimise [her] complaint and portray … the suffering as worthy of the complaint” (Pomerantz, 1986, p. 228; Rogers & Todd, 2010) in the face of doctor’s expectation that she is doing better.

Doctor invites more elaboration with a continuer, ‘yes °and°’, and, in overlap with the softly uttered second half of doctor’s response, patient continues her troubles-telling, again with emphasis and hyperbole: ‘and the ↑food has no taste either I ↑do eat but what I eat I cannot taste anything anymore and that has been for the ↑last (.) three weeks↑ it has been a disa:ste:r’. This leads doctor to conclude ‘so gotten worse actually↑’.

In sum, apart from the general gloss of wellness at the very start of the interaction, patient formulates unmitigated distress, which continues and is emphasised in the rest of the consultation (not in transcript). Patient is actually doing worse than before, and she constructs her problems as related to after-effects of the treatment she received (‘that second operation’). Patient does not seem to feel the need to talk wellness into being by mitigating her problems. Stressing the strength of her distress, she makes her problems doctorable (Heritage & Robinson, 2006a), i.e. worthy of medical attention.

4.0 Discussion and Conclusion

The results of the analyses mostly reconfirm the earlier research findings discussed in section 2.0. Thus, the doctors in the data frequently orient towards wellness by means of yes/no questions that are designed to elicit ‘no problem’ responses (25 out of 28 consultations; see e.g., Beach, 2013; Boyd & Heritage, 2006). In Data 1, 2 and 5, this type of question is being used to confirm that patients have no complaints in the area affected by malignancies and are eating and drinking well. It has been observed in the literature that doctors use yes/no questions oriented towards ‘no problem’ answers as a tool to enable them to work through their medical agenda quickly and efficiently (see e.g., Beach et al., 2005; Beach 2013; Beach, 2014; Ford et al., 1996; Heritage & Maynard, 2006b). Since the doctors in the current study are – like many of their counterparts in other hospitals – limited to a schedule of 10 to 15 minutes per consultation, this need for efficiency may play a role.

As in earlier research, these data show patients giving positive news, either spontaneously or in answer to the doctor’s questions (26/28), and confirming physicians’ no-problem statements (23/28) (see e.g., Beach, 2013; Boyd & Heritage, 2006). Data 1, 2 and 5 show such ‘no problem’ answers, with the patients confirming wellness and sometimes listing the areas in which they are doing well. The data also show patients minimising (22/28; Data 2) or completely denying (1/28, Data 7) their symptoms (see e.g., Beach 2013; Jarret & Payne, 2000, Roger & Todd, 2010). It has been suggested that patient responses which minimise or deny symptoms might be instances of constraints of the ‘ordinary world’ spilling over in the medical world: “the general ‘troubles resistance’ that is normally required of persons in the social world manifests itself in the medical visit” (Heritage & Robinson, 2006a: 75; see also Jefferson, 1988). Beach (2013) and Rogers & Todd (2010) suggest minimising and denying symptoms might be part of a coping strategy, trying to conceal fear of potential cancer recurrence or progression (Rogers & Todd, 2010: 276), or to ward off further treatment (Beach, 2013). Physicians, in their turn, also minimise patients' symptoms in an attempt to reassure patients (see e.g. Data 2: 'that is something that eh:: (.) that you do see improving in the course of time'). This interactional behaviour on the part of doctors occurs in six out of 28 consultations in the data.

Similar to observations in earlier studies (e.g., Beach, 2014; Jones, 1997), during the physical examination the doctors in the data give positive assessments of what they see when they are examining patients (see Data 3 and 4). And in 13/28 consultations – especially during the rounding off (after the physical) but also at other points during the consultation – patients orient towards wellness by claiming to be working actively towards a healthy lifestyle (Beach, 2013; see Data 4).

The doctors also employ 'framing' to talk wellness into being. In Data 2 doctor seems to define 'improvement of patient symptoms' as the benchmark for wellness ("is it going better and better?"), after patient has supplied a neutral assessment of his condition. Reframing wellness also occurs in the opening question that doctors use in the corpus (cf. Chapter 3), e.g., in Data 6: doctor qualifies her HAY? question by adding 'in the circumstances', thus framing wellness as the relative wellness that can be expected from recovering cancer patients. This modification of the ritual opening creates the affordances for patient to offer a positive, wellness-oriented answer to the question.

Problem orientation, however, also occurs frequently in the data. During anamnesis, patients use emphasis and hyperbole to foreground distressful after-effects of the malignancy and its treatment (Data 6 and 8) and doctors acknowledge patients' problems (Data 6) and ask problem-oriented questions, which receive problem-related answers (Data 8). During the physical examination, doctors report on problematic observations (Data 7).

The data yielded a striking characteristic in the way problem-oriented turns were performed: with the exception of Data 8, the *first nomination* of current problems, by *both* doctor and patient, was always marked by delay, hesitation, self-repair and mitigation. It may be concluded, therefore, that although the discussion of problems can certainly be seen as a legitimate part of the agenda of the consultation, a detailed analysis of the interactional enactment of the presentation of problems shows that this orientation is 'dispreferred' in the – conversation analytical – technical sense (Schegloff, 2007). Mazeland (2016) refers to such responses as 'complex' and Clift (2016) as 'reluctant'. It seems as though raising problems is somehow unexpected and outside the ‘norm’ in the circumstances. Therefore, it can be concluded that by marking the first nomination of problems as complex or dispreferred, participants discursively co-construct a ‘default’ orientation towards wellness for the consultation. Whether or not such a pervasive orientation towards wellness might actually inhibit patients from mentioning problems is a point that needs further investigation.

Finally, a few remarks on the notions of ‘wellness’ and ‘problem’. In previous research on doctor-patient communication in the oncology consultation, wellness is mostly equated with absence of cancer: patient being free of recurrence, metastasis or second tumours. Patients’ focus on this ‘core’ wellness is reported, for example, in Beach’s (2013) study of 75 oncology consultations at a comprehensive cancer clinic, which finds that patients “downgrade and dismiss potentially troubling symptoms [...] as normal / stable, improving, or easily managed [... as] evidence to ‘justify their wellness,’ [...], and thereby reduce reasons to be concerned that may trigger additional diagnostic efforts and initial or recurring treatments” (p. 579). A Swedish study of follow-up consultations of testicular cancer survivors (Sandén et al., 2001) shows an orientation of both doctors and patients towards this core wellness of the (continued) absence of cancer: “[t]he routines involved in the delivery of information of test results are used as recurrent opportunities for the parties to confirm that the situation is under control, that ‘everything is OK’” (p. 145). In the data in this paper, however, doctors and patients are seen to orient towards various different types of wellness: the wellness of not having cancer (Data 3, 4), of having fewer or milder symptoms (Data 1, 2, 5), of being a ‘normal’ patient (Data 2) and of working towards health (Data 4). In the follow-up cancer consultation, wellness is a gloss for different dimensions of physical, emotional and psychosocial well-being. The data also show different types of ‘problem’: tell-tale symptoms of recurrence in Data 1, short-term after-effects of the tumour and its treatment in Data 2 and 6, and long-term after-effects in Data 7 and 8.

It can be argued, then, that the notions of ‘wellness’ and ‘problem’ in research on cancer consultations are in need of refinement. Further research in a larger corpus might yield insight into the exact meaning of these concepts, and into how the different types of wellness and distress influence the way doctor and patient discuss them, e.g., whether after-effects are mitigated in the same way as possible signs of recurrence, and whether short-term after-effects are discussed with the same intensity as long-term after-effects.

Chapter 5: An exploration of the effects of the DT+PL on the contextual parameters and the structure of the interaction in cancer follow-up consultations[37]

1.0 Introduction

The DT+PL has been implemented as a discussion tool in many hospitals in The Netherlands (Van der Linden & Hoekstra-Weebers, 2016; Van Nuenen et al., 2017) and abroad, with the aim to make sure that all possible areas of distress are included in the consultation, and that psychosocial distress is not overlooked. As observed in the Introduction to this thesis, socio-medical studies on the effectiveness of the DT+PL and comparable quality-of-life screening tools have shown mixed results (Girgis et al., 2018; Kotronoulas et al., 2014; Palmer et al., 2011). Some studies report more frequent discussions of psychosocial distress (Detmar et al., 2002; Velikova et al., 2004), better targeted referrals (Van Nuenen et al., 2017), and patients commenting positively on the tool (Van Nuenen et al., 2018), while others conclude that such screening tools have little to no effect on patients' quality of life (Boyes et al., 2006; Hollingworth et al., 2013). Irrespective of the outcomes of these studies, what remains under the radar in quantitative research designs is how the implementation of this type of instrument impacts the lived experiences of the participants in the consultations themselves. To my knowledge, there is only one qualitative study that addresses this issue. Biddle et al. (2016) use *interview* data to investigate how both doctors and patients experience the introduction of the DT+PL. This chapter builds on their research with a case study that does not only draw on interviews but also on *interactional* data from actual consultations with the DT+PL conducted in one of the main cancer centres in The Netherlands. This will show not just how doctors and patients reflect on the use of the DT+PL, as in Biddle et al. (2016), but it will also highlight how its introduction impacts doctor-patient discourse during the

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consultation, and how doctors and patients negotiate the affordances and constraints created by the tool.

Since medical consultations are well-defined institutional communicative events with clear roles, norms and expectations (Ten Have, 1989; Chapter 2), the assumption is warranted that the introduction of the DT+PL will have consequences for the organisation of the consultation as a *speech event* (Hymes, 1977). Therefore, the research question in this chapter is: in what ways does the implementation of the DT+PL impact the contextual parameters of the Dutch follow-up cancer consultation, and how do these effects resonate in the interactional organisation of the encounter?

2.0 Expected effects of the DT+PL

Chapter 2 describes the standard follow-up cancer consultation as a speech event, using the SPEAKING model as a heuristic tool. The model comprises the contextual parameters Setting (time and place), Participants and their roles, Ends or aims, Act sequence, Key, Instrumentalities (channels of communication), Norms and Genre (Hymes, 1977; Saville-Troike, 2003).

The implementation of the DT+PL can be expected to affect the contextual parameters of the standard consultation on different dimensions. The introduction of this new Instrumentality (a written form carrying extra information about the patient) by default adds a new item to the agenda of the consultation and consequently another End: the discussion of the physical and psychosocial problems the patient has indicated on the PL. This will have to be negotiated without exceeding the 10-15-minute time limit that has been set for the consultations. The tool may also influence both the routine Act sequence (at what point in the consultation should it be brought up?), and the Participant roles of both patients (who get added agency by the opportunity to nominate particular topics) and doctors (who are trained to deal with biomedical issues and not necessarily with the psychosocial problems that are also featured in the PL). Finally, introducing the discussion of psychosocial problems may affect the Key of the interaction.

The analyses below aim to show how these projected effects surface in the comments of the physicians about the new tool, and how the introduction of the DT+PL plays out in the discursive construction of the consultations.

3.0 Results

The analysis of the data below is organised in terms of a selection of features from the SPEAKING model: Ends and Participant roles, Act Sequence, Setting (the time element), Key and Instrumentalities. Elements of the model where little or no impact was observed (Norms and Genre) have been left out. Each section will first focus on what will be referred to as *meta-data*: how participants in the training session and in the interviews report on that particular aspect of the speech event, and the (expected) impact the DT+PL has on this. This picture is then refined by means of the *interactional data*: a turn-by-turn analysis of typical extracts from the doctor-patient interaction in the DT+PL consultations (see Chapter 1).

3.1 Ends and participant roles

In the interviews with the doctors, they are very clear about what they see as the most important Ends or aims of the follow-up consultations, as illustrated in Data 1 and 2:

Data 1

Interview Dr D

Look, if someone has had an operation and everything is OK, well, then I ask how things are, and whether there are any complaints, and then I check them over very carefully, and then they are on their way home within a few minutes. And then they are really pleased to be outside again so quickly. […] And if they have complaints then of course they are afraid that the complaints are related to the disease and that it has returned. Then the aim is to reassure them as fast as possible. So that means doing the physical examination a.s.a.p.

Data 2

Interview Dr A

Check if patient is doing OK, if there is no tumour, so that is the medical, content, business part, the oncological part. Apart from that, it is important whether patient needs to rehabilitate as far as that is possible, so primarily from the patient’s perspective.

Both doctors indicate that monitoring patients for signs of recurrence, metastasis and second tumours, checking how they are coping with after-effects, and relieving their anxiety on these issues are central to their aims. They do not seem to be focussed on psychosocial distress, similar to doctors in other reports on the subject (see, e.g., Beach et al., 2005; Ford et al., 1996; Zhou et al., 2015). This can be seen in Data 3, in which Dr D responds to the question whether he discusses psychosocial issues with his patients:

Data 3

Interview Dr D

`I do discuss it, but I am in principle I am a head and neck surgeon. So that discussing psychosocial issues is not my job […] you need to stick to what you are good at […] we have a supportive team for that […] so you can easily refer patients to them.`

Data 3 shows that Dr D is quite outspoken about what he considers to be his 'job', and makes clear that discussing the psychosocial distress his patients might suffer from is not central to it; other people are better qualified for this (see Biddle et al., 2016).

Dr A on occasion will counsel patients if she has 'a good click with someone so have a feeling that I can be of some use' (see Chapter 2). However, in terms of structural attention to psychosocial issues, she seems to share Dr D's views. During the training session she explains her position by pointing at what she feels as her lack of expertise in the matter:

Data 4

Training session

`Dr A: we have not been trained for this at all […] I am not competent to judge this. I cannot judge whether someone has psychological issues […] and should be referred to a psychologist. I can't judge if that is necessary […] tired is a cause or a result, and to judge that, for that you need a professional.`

This perceived lack of training in how to recognise indirect signals of psychosocial distress and how to distinguish expected levels of distress from excessive, problematic ones is an important reason for the lack of focus on such issues of the physicians. They say that, as oncological surgeons, they view patients and their complaints through a medical lens: they are trained to treat physical conditions and this is the expertise that they will automatically rely on – and go back to – when they are confronted with a patient's problem, as is illustrated in Data 5:

Data 5

Interview Dr D

`yes we only look at eh, tired? Low Hb level, and that is as far as we get, right, as a matter of speaking.`

The data above suggest that implementation of the DT+PL may compel doctors to come out of their comfort zone. The tool will force them into *structurally* engaging with psychosocial distress, an area that they do not feel expert in.

The DT+PL may also have an impact on the *interactional roles* of doctor and patient, as the oncological nurse puts it during the training session:

Data 6
Training session

Trainer: Of course, with this tool you give the patient the lead in the interaction: these are the problems, this is what I want to discuss.

In Data 6 the trainer spells out one of the interactional effects of the introduction of the DT+PL: the tool will give patients *agency*, in the sense that they will be given an active role in the selection of 'mentionables', i.e. points worthy of and suitable for discussion during the event (Button & Casey, 1984; Schegloff & Sacks, 1984/1973). The trainer indicates that the information the patients supply in the PL needs to be constructed as an extra item on the 'agenda' of the consultation. In this way, the DT+PL functions as a topic elicitor and its content as a topic pre-nominator.

The interactional data from the consultations themselves show, however, that doctors still have a crucial role in the on-line discursive construction of the topic initiation during the event, as can be seen in Data 7:

Data 7
Dr A

[Patient's DT score is 6 with six problems crossed on the PL, two of which are emotional (fear and tension). Data start after nine minutes. During anamnesis doctor and patient extensively discussed patient's headaches and problems with excessive earwax]

```
P1      Dr: °shall I just°             °zal ik nog even°
            meanwhile look             vast hier naar
            at th:↑s (1.7)             kij:k↑en (1,7)
            ((picks up DT+PL))         ((pakt DT+PL))
            ((coughs)) (1.9)           ((kucht)) (1,9)
            °let's just see°           °even kijken°
            well you write eh:         nou u schrijft eh:
            down that you:             op dat u:
            are a bit fearful and      wat angstig bent en
            eh have [tensions↑         eh [spanningen heeft↑
P2      Pt:         [well yes             [nou ja
            that [goes]                dat [gaat]
P3      Dr:      [yes ]                    [ja  ]
P4      Pt: together doesn't it        samen hè
            tension and fear           spanning en angst
            [that] is how it [feels]   [dat] is hoe het [voelt]
            kind of                    zeg maar
P5      Dr: [yes ]           [yes  ]   [ja]             [ja   ]
            that is [it too: ]         dat is [het oo:k ]
```

P6	Pt:	[but that] may in ((gestures)) principle have to do with that with that ear with that head which to [me] really eh (0.3)	[maar dat] kan in ((gebaart)) principe te maken met die met dat oor met dat hoofd wat voor [mij]toch wel eh (0,3)
P7	Dr:	[yes]	[ja]
P8	Pt:	is strange [and]	vreemd is [ook]
P9	Dr:	[yes]	[ja]
P10	Pt:	in that sense strange ehm (1.3) yes that you are worried of course that is of course all that you think (.) there's a tumour in me head	in die zin vreemd ehm (1,3) ja dat je je ongerust maakt natuurlijk dat is natuurlijk al dat je denkt (.) er zit een tumor in me hoofd

By relaying what the patient has indicated on the form (P1), i.e. that he suffers from fear and tension, doctor discursively constructs mutual orientation to these problems. Patient reacts to doctor's nomination of fear and tension with the observation that the two go hand in hand (P2, P4). He only now – *in response to doctor's prompt* – links them with the physical problems he has with his ear and his head (problems which he and doctor have just discussed at great length), saying (P6): 'but that [the tension and fear] may in principle have to do with that with that ear with that head'. So, although patient pre-nominated anxiety and fear in the PL before the consultation and so put it on the 'agenda', the doctor actually *topicalised* patient's psychosocial distress in the interactional event.

Although the dataset shows that the DT+PL indeed succeeds in creating the affordances for patients to co-set the agenda for the event, at the same time the information patients indicate on the PL+ DT about their concerns is not always complete, and doctors are sensitive to this, as is illustrated in Data 8.

Data 8

Dr D

[Patient's DT score is 0; only two items crossed on the PL (dry itchy skin and dizziness). Data begins at opening consultation.]

P1	Pt:	here you are ((hands DT+PL to Dr))	alstublieft ((overhandigt DT+PL aan Dr))
P2		(4.8) ((Dr checks DT+PL))	(4,8) ((Dr bekijkt DT+PL))
		Lines left out	
P3	Dr:	looking ↑good (0.2) ((closes DT+PL and puts it to one side))	ziet er goed ↑uit (0.2) ((sluit DT+PL en legt hem weg))
P4	Pt:	I thought so too=	dacht ik ook=
P5	Dr:	=great yes	=helemaal goed ja
P6	Cp:	((directs gaze at patient))	((kijkt naar patient))

P7	Pt:	okay (1.3)	oké (1.3)
P8	Dr:	no new complaints otherwise [or eh=	geen nieuwe klachten verder [of eh=
P9	Pt:	[=no	[=nee
P10	Cp:	[=well=	[=nou=
P11	Pt:	=yes my wife saw here ((points at side of head)) here on that side some some (.)	=ja mijn vrouw zag hier ((wijst naar zijkant hoofd)) hier aan die kant wat wat (.)
P12	Cp:	according to m[e I saw that last time as well	volgens mi[j heb ik dat vorige keer ook gezien
P13	Dr:	[yes	[ja
P14	Cp:	and Monday morning cutting his hair	en maandagmorgen met z'n haar knippen
P15	Dr:	yes	ja
P16	Cp:	there was a little scab= =wi wi with the same shiny mother-of-pearl spot=	zat daar een korstje= =me me met hetzelfde glanzende parelmoerplekje=
P17	Dr:	=uhu we are going to have a look	=uhu we gaan even kijken

The information on the DT+PL indicates that the patient seems to be doing well. On the basis of this, in P3-P7 doctor and patient co-construct an orientation to wellness, with the doctor in P5 using extreme language 'great yes' to upgrade his assessment (Beach, 2013; Pomerantz, 1986). Then, after a short pause, doctor re-checks with a 'no-valenced optimised' question, 'no new complaints otherwise'. The preferred response to this type of question would be a confirmation, reporting a positive health outcome (Heritage, 2010). The doctor's addition of 'or', however, cancels the preferred response and opens up the option of relating a negative health outcome. Patient's answer to the question is in line with the wellness orientation of the interaction before this point (P9), but his 'no' overlaps with companion's 'well' – a discourse marker that signifies disagreement (a 'complexity marker', see Mazeland, 2016). Patient immediately latches on to his companion's interruption (P11) and takes over by reporting what she has noticed (and probably was about to bring up herself): 'my wife saw here ((points at side of head)) here on that side some some'. At this point companion takes over completely and tells doctor her point of concern: a small shiny spot that she discovered when she was cutting patient's hair. With patient's medical history (melanoma on the ear) unexplained spots would clearly constitute a warning signal to patient and companion, but the concern was not indicated in the PL. Sensitive to their worry, doctor responds immediately (P17) and shows them that he is taking the complaint seriously by announcing: '=uh we are going to have a look'.

Data 8 shows that, although the DT+PL affords patients the agency to nominate topics for discussion, patients sometimes omit to indicate problems on the PL that are relevant for discussion in the consultation – be it through forgetfulness, because they doubt the legitimacy of their concerns, or for other reasons (e.g., that patients do not consider this doctor or this occasion to be the relevant platform to discuss certain issues) (see Biddle et al., 2016). Sometimes prompted by the doctor and sometimes spontaneously, patients on average nominate just over two issues outside the PL per consultation. The physicians in the data seem very aware of this possible incompleteness; again and again they check and recheck patients' self-assessments.

In the training session the doctors and the trainer discussed the possibility that the DT+PL would increase the potential agency of patients to put the discussion of psychosocial distress on the agenda of the consultation. The interactional data show that the DT+PL can indeed put psychosocial concerns on the agenda. Doctors then have an important role in actually initiating these topics for discussion, with the patients responding to explicit openings by the doctor.

3.2 Act sequence

As discussed in Chapter 2, the standard follow-up cancer consultation has a clear Act sequence. An important question, therefore, is *at what point* in the consultation the content of the DT+PL form should be brought up. In the training session this dilemma is addressed by the oncological nurse:

Data 9
Training session

`Trainer: You first just need to consider when the Distress Thermometer gets to be discussed – first physical examination and then pay attention to the Distress Thermometer for a while, or first the Distress Thermometer and then switch to the physical examination.`

The trainer here reduces the issue of the timing of the discussion of the DT+PL in the consultation to a simple, binary choice (either before or after the physical examination of the patient), but Dr D's response shows that he feels that the situation is more complex:

Data 10
Training session

`Dr D: […] because usually the people are still nervous when they come, and they are only de-nerved, if you like, if it is OK. You cannot postpone the physical for too long […] they are on tenterhooks. So I don't think that you can do this first [`*`i.e., discuss the DT + PL`*`].`

```
First the physical examination needs to be completed, I think […] but
on the other hand you do want to, because you want to - the first
question is 'How are things?' That is your first strike always - then
you know how things are, right.
```

Clearly, Dr D is in two minds about the best slot in the consultation for the discussion of the DT+PL: on the one hand, he feels the physical examination should be done as early as possible, since patients need to be reassured that they are – at this point in time – free from cancer; on the other hand, it seems to him that the topic would naturally tie in with the 'How are you?' (HAY?) question that routinely signals the opening of the consultation proper (see Chapter 3). He does not commit himself to any choice, but Dr A formulates a clear plan of action:

Data 11
Training session

```
Dr A: So I think that I will just look physically, what are the
physical complaints, then I'll ask my own questions, and then I'll
say, I'll just say, I will be happy to go into it into the questions
on the Distress Thermometer after the examination. I just want to
check whether that is all OK first.
```

After careful consideration, Dr A decides that she will only discuss the DT+PL after she has performed her normal routine and she is sure that 'all is okay'. Note how she defines 'okay' as an exclusively medical state.

Dr D, however, detects a problem with this strategy:

Data 12
Training session

```
Dr D: But then you've got, yes then it is like a bit repetitive, right
because if you say, 'How are things?', then you will probably broach
the first big topics […] and later you would have to come back to
that.
```

It is clear that Dr A and Dr D feel they are facing a dilemma in terms of Act sequence. Should they discuss the DT+PL immediately after the 'How are you?' question, after the anamnesis, after the physical examination or at the very end of the consultation when everything they 'normally' do has been said and done, with the possibility that repetition creeps in, and consequently, that time limits are exceeded?

In the end both doctors chose to discuss the DT+PL – in varying degrees of detail – during anamnesis, finishing its discussion *before* the physical examination, in all consultations in the current dataset. The data below illustrate the consequences of this choice for the interactional organisation of the encounter.

In Data 13 Dr A mentions the DT+PL at the start of the consultation, but then explicitly postpones its discussion to a later moment:

Data 13
Dr A

[Patient’s DT score is 6, which signifies considerable distress, with six items crossed on the PL, two of which are emotional (fear and tension). Data start at the beginning of the consultation, just after participants have entered the consultation room.]

P1	Dr:	yes hehehe (0.5) (okay) (2.1) ((sits down)) so:(1.3) [((Pt sits down, envelope in his hand)) [had you received the note for the project or not↑	ja hehehe (0,5) (oké) (2,1) ((gaat zitten)) zo:(1,3) [((Pt gaat zitten met envelop in de hand)) [had u het briefje van het onderzoek meegekregen of niet↑
P2	Pt:	eh ye:s (.) [this one] yes (0.6) ((takes DT+PL from envelope and unfolds it))	eh ja: (.) [deze] ja (0,6) ((haalt DT+PL uit envelop en vouwt hem open))
P3	Dr:	[okay] I’ll look at it in a minute first just the standard ((stretches out her hand)) (0.8)	[oké] ga ik zo even naar kijken eerst even het gewone ((steekt hand uit)) (0,8)
P4	Pt:	I have a( ) is at the [desk]	ik heb een ( ) is bij de [balie]
P5	Dr:	[good]	[mooi]
P6	Pt:	already handed over some things ((gives Dr DT+PL))	al het één en ander afgegeven ((geeft DT+PL aan Dr))

After doctor and patient have entered the examination room and settled down, Dr A establishes the procedure she intends to follow for the DT+PL (P3). Being handed the form, she topicalises it by saying ‘I will look at it in a minute’, deferring the discussion of the DT+PL to an undefined but not far-off point in the future of the consultation. She immediately adds ‘first just the standard’, further clarifying her agenda for the consultation: she will stick to her normal routine, i.e. first go through the steps of her ‘ordinary’ consultation before she discusses the DT+PL, implying that it will come to the table as an extension of her normal routine.

Just as Dr D predicted in Data 12, when doctors first ‘do what they always do’ – i.e. first take a complete anamnesis – and only then go through the DT+PL, the result might be that points that have already been addressed are revisited. Sometimes, however, this strategy creates affordances for new insights into the patient’s condition, as illustrated in the data below.

Data 14

Dr A

[Patient’s DT score 7.5 (high distress), with 25 elements crossed on the PL, seven of which are emotional (emotional control, self-confidence, fears, depression, tension, loneliness, loss of control). Doctor and patient have already discussed a number of after-effects that patient still experiences, and then discussed various points on the PL.]

P1	Dr:	hHh hey I say, what I (.)	hHh hee zeg, wat ik (.)
		what I do notice with you	wat me wel opvalt bij u
		(.) because quite a number	(.) want een heel aantal
		of things [those]	dingen [dat]
		I did really [already] know	wist ik eigenlijk [ook] wel
P2	Pt:	[yes]	[ja]
		[yes]	[ja]
P3	Dr:	hHh is that ehh (.) that you	hHh is dat ehh (.) dat u
		are after all also a little	toch ook wat
		more anxious and depressed	angstiger en neerslachtiger
		[right]	bent [hè]
P4	Pt:	[yes] sometimes I am yes	[ja] soms wel ja

On checking the DT+PL, doctor communicates to patient that, although the form contains mostly known information (P1), she has found something she thinks should be brought up: patient’s depression and anxiety (P3). She implies she was not aware of this by means of the Dutch discourse marker *toch* – roughly equivalent to ‘after all’ – which indicates that speaker’s assumptions have been inverted (see Zeevat, 2000). She introduces the topic hesitantly and prefaces it with much delay and a raft of discourse markers ‘hHh is that ehh (.) that you are after all also a little’. This mitigates the possibly face-threatening act (FTA; Brown & Levinson, 1987/1978) of introducing the sensitive topic of emotional/mental problems such as anxiety and depression, and may also be indicative of the doctor’s diffidence to discuss these issues (see Biddle et al., 2016; Chapter 7). Patient confirms that she suffers from anxiety and depression (P4) but at the same time mitigates their scope ‘sometimes I am yes’.

In some consultations in the dataset, the DT+PL itself can be seen to present an interactional dilemma for the physician in the opening stage of the consultation: the presence of a form with information on the physical, spiritual and psychosocial well-being of the patient, filled out just minutes before the event begins, infringes on the ritual opening of the consultation, as is shown in Data 15:

Data 15
Dr D

[Patient's DT score is 0; no items crossed on PL. Data from opening of consultation. Patient has taken the DT+PL from her bag and put it in front of the doctor on his desk]

P1	Dr:	(0.9) ((picks up the DT+PL and looks at Pt)) look ((waves DT+PL back and forth)) ((joking tone)) I also don't have to ask you anymore how you are doing because eh:	(0,9) ((pakt de DT+PL en kijkt Pt aan)) kijk ((beweegt DT+PL heen en weer)) ((grappende toon)) ik hoef ook niet meer te vragen hoe het met u gaat want eh:
P2	Pt:	yeahh	jahh
P3	Dr:	you have °filled° this out already ((holds up DT+PL)) ((all smile broadly)) (.)	u heeft dit al inge°vuld° ((houdt DT+PL omhoog)) ((allen glimlachen breed)) (.)
		lines left out Dr reads DT+PL and chats with Pt	
P4	Dr:	how is it with you (.) other than that↑	hoe is het met u (.) verder↑
P5	Pt:	well fine	nou prima
		lines left out chitchat	
P6	Dr:	no complaints↑	geen klachten↑
P7	Pt:	no	nee

By opening the consultation (P1) with '[I] don't have to ask you anymore how you are doing because eh: you have already °filled° this out', doctor makes explicit the interactional dilemma that is the consequence of the procedural arrangements regarding the DT+PL. The fact that patient hands the filled-out form to the physician before the beginning of the consultation proper affects the routine Act sequence: it effectively compromises the ritual opening HAY? question that all but one of the standard consultations in the dataset begin with (see Chapter 3), and may render (parts of) the anamnesis superfluous. The DT+PL is at this point in the consultation constructed as supplying doctor with all necessary information about the situation of the patient, and since it is dispreferred to ask for known information (this would be violating Grice's Maxim of Quantity; Grice, 1975), the doctor is robbed of his ritual opening. The dilemma is recognised by all involved: doctor's remark is met with broad smiles (P3). After reading the DT+PL and some chitchat (not in transcription in Data

15), however, doctor *does* ask his HAY? question after all (P4), creating relevance for the question (see Sperber & Wilson, 1987) and solving his interactional problem by adding the qualification ‘other than that’, to open the possibility of nominating complaints that may not have ended up on the form. The meta-data show that doctors were doubtful about when and how to introduce the discussion of the DT+PL in their consultations. They were not sure whether to discuss the document before or after the physical examination; they worried that its discussion might extend patients’ anxiety about possible recurrence; and they surmised that it might interfere with the ‘normal’ interactional routine of the consultation. The interactional data show that the doctors in all cases opted for the discussion of the DT+PL before the physical examination, as part of anamnesis. They show doctors explicitly managing the Act sequence of the consultation to accommodate the discussion of the DT+PL at an opportune moment (Data 13), and being acutely aware of the impact the DT+PL has on their normal routine of opening the consultation with a ‘How are you?’ question (Data 15). The risk of repetition they discussed in the training session turns out to be warranted, but it may also lead to new patient problems being discovered, which otherwise might have remained undiscussed.

3.3 Setting: Time

As mentioned in section 2.0, the doctors in the hospital are restricted in the amount of time they can spend on the individual consultations. If they exceed the 15-minute timeslot, this has real-world consequences for all parties involved. Time is, therefore, a prime concern for the doctors in their discussions of the consequences of the implementation of the DT+PL (see Biddle et al., 2016), as can be seen in the data below:

Data 16
Training session

```
Dr D: if you have to engage with this […], there is very little time
already, and this will cost a lot of time, one way or another.
Dr A: it all costs money and time, and that is simply not available.
```

However, when comparing the duration of the consultations of the two doctors who participated both in de Control study and the DT+PL study, it turns out that the DT+PL may not be the only factor influencing the duration of the consultation: the average duration of the consultations varies considerably, both between doctors and between conditions (with and without the DT+PL), as can be seen in Table 1.

In the Control group, Dr A's consultations took 13:05 minutes on average, versus 8:04 minutes for Dr D's. Dr A's DT+PL consultations took 22:56 minutes on average, whereas Dr D's took 8:30 minutes. So in both conditions, Dr A's consultations took (much) longer than Dr D's. Dr A's DT+PL consultations took almost 10 minutes longer than her Control group consultations, whereas Dr D's DT+PL consultations on average took roughly the same amount of time as his Control group consultations, around eight minutes. Also, there is considerable variation within each group, and Dr A's consultations were more varied in duration than Dr D's. Dr A's consultations vary between 05:20 and 51:50, and Dr D's between 04:19 and 12:49.[38] In Dr A's Control group the standard deviation from the average is 04:36 minutes, but in her DT+PL group it is much higher still, 15:57 minutes. In Dr D's Control group SD is 03:34, and slightly lower still in his DT+PL group, 02:56. This variation in the duration of the consultations suggests that increased duration cannot simply be explained by the introduction of the DT+PL; there is quite a large difference between the two doctors, both with and without the DT+PL.

Dr A				Dr B			
Control group		DT+PL group		Control group		DT+PL group	
	Duration		Duration		Duration		Duration
1	15:13	1	37:12	1	10:39	1	10:10
2	08:55	2	05:20	2	04:49	2	07:44
3	13:49	3	28:20	3	12:49	3	12:44
4	08:14	4	10:13	4	10:09	4	05:42
5	20:23	5	51:40	5	05:39	5	06:12
6	15:26	6	11:18	6	04:19		
7	08:04	7	26:38				
8	09:27	8	12:50				
9	18:17						
Average	13:05		22:56		08:04		08:30
SD	04:36		15:57		03:34		02:56

Table 1 Duration of consultations in Control group and DT+PL group per physician

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[38] This variation tallies with what came out in informal discussions with the various doctors in the department. In any clinic, with or without the DT+PL, the consultation times vary: short consultations with patients who have few problems alternate with long ones with patients who turn out to have bad test results, symptoms of recurrence, etc.

One possible reason for this difference may be the problem load of the patients, i.e. the total of the number of items crossed on the PL plus the number of issues outside the PL that they raised during the consultation. A comparison of the average problem load of the patients shows considerable variation between doctors and conditions (see Table 2).
Comparing the problem load per doctor, we see that in both conditions, Dr A's patients on average have a higher problem load than those of Dr D: roughly 20% higher in the Control group, and twice as high in the DT+PL group.

	Dr A		Dr D	
	Control group	DT+PL group	Control group	DT+PL group
Number of patients	9	8	6	5
Problems indicated on Problem List	77	106	40	35
Problems nominated by patient outside Problem List	14	26	7	4
Total problem load	91	132	47	39
Average problem load per patient	10.11	16.5	7.83	7.8

Table 2 Average problem load per patient

Also, the problem load of Dr D's patients is – on average – stable in the two conditions, whereas the average problem load of Dr A's DT+PL group is more than 50% higher than that of her Control group. The higher problem load of Dr A's patients in both conditions, then, might partly explain the longer duration of her consultations: there was simply more to discuss.

	Dr A		Dr D	
	Control	DT+PL	Control	DT+PL
Number of patients	9	8	6	5
Average problem load per patient	10.11	16.5	7.83	7.8
Average number of problems discussed per patient	3	10.4	3.33	2.8
Percentage problems discussed	30%	63%	42%	36%
Time average per consultation	13:05 mins/sec	22:56 mins/sec	08:04 mins/sec	08:30 mins/sec
Time average per problem discussed	4:21 mins/sec	2:12 mins/sec	2:25 mins/sec	3:02 mins/sec

Table 3 Duration of consultation related to number of problems in Control group and DT+PL group per physician

There is also a difference in the number of problems that is actually addressed, and the time devoted to their discussion (see Table 3).

For Dr D, the average number of problems of the patients and the duration of the consultations remain stable over the two conditions. However, the average number of problems discussed per patient goes down in the DT+PL group (2.8 versus 3.33), the percentage of problems discussed is slightly lower (36% versus 42%), and the time spent per problem goes up by 35 seconds on average. For Dr A, the average duration of the consultations in the DT+PL group is almost double that of the Control group, the number of problems discussed more than triples, a much larger percentage of the patients' problems is discussed (63% versus 30%), but – in spite of the longer duration of the DT+PL consultations – the time per problem discussed is almost halved.[39]

Where Dr D discusses more or less the same number of problems per patient in more or less the same amount of time in both the Control group and the DT+PL group, Dr A discusses almost three times as many problems per patient in the DT+PL group than in the Control group, and her DT+PL consultations are almost twice as long. These differences may be due to the way in which the two doctors handle the discussion of the DT+PL: Dr A tended to first go through her normal routine and then discuss the DT+PL, usually starting with items that stood out to her and then discussing the items ticked by patient one by one (see, e.g., Data 7, 13, 14), whereas Dr D focussed the discussion of the DT+PL on 'new' complaints (see, e.g., Data 8, P8), thus limiting the number of issues discussed.

In the meta-data doctors expressed their concern that the introduction of the DT+PL would lead to longer consultation times, and the figures on duration seem to bear them out. However, the interactional data reveal a number of factors that affect the duration of the consultations and account for the differences between the doctors: not so much the introduction of the DT+PL itself causes the increase in problems discussed and therefore in the duration of the consultation, but rather matters such as patients' problem load and doctors' strategic approach to the implementation of the discussion of the DT+PL in the consultation.

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[39] It should be noted that the averages of time-per-problem are deceptive, since sometimes almost an entire consultation could be devoted to one problem, sometimes combined with a quick mention of a large number of others, and in other consultations there are hardly any problems to discuss.

3.4 Key and Instrumentalities

Since the DT+PL by definition measures distress – it is, after all, a *Distress* Thermometer plus *Problem* List – its introduction warrants the expectation that the consultations will become more problem-oriented. This was one of the worries expressed by the doctors in the DT+PL study as illustrated in Data 17:

Data 17
Training session

`Dr D: with every point you could open up a sort of cesspool of problems`

The doctors feared that the DT+PL might lead to an avalanche of problems to discuss, which might affect the Key or mood of the consultation. The interactional data, however, show that in the DT+PL consultations there is a similar *mix* of positive and negative Key in the way these problems are formulated as in the Control group consultations: problems may be emphasised, but they may also sometimes be mitigated or denied; patients may emphasise their wellness in positive glosses after doctor's opening HAY? question, but immediately follow them up with a (mitigated) account of remaining problems (see Chapter 3); and sometimes the DT+PL itself is used to construct a positive Key.[40] Two sets of data will illustrate this.

A closer look at Data 7 shows that patient emphasises and elaborates on his fears, and establishes them as a natural reaction to cancer, thus focussing the discussion on problems and distress.

Data 7 (repeated)
Dr A

[Patient's DT score is 6 with six problems crossed on the PL, two of which are emotional (fear and tension). Data start after nine minutes; in anamnesis doctor and patient extensively discussed patient's headaches and problems with excessive earwax]

```
P1    Dr: °shall I just° meanwhile      °zal ik nog even° vast hier
          look at th:↑s (1.7)           naar kij:k↑en (1,7)
          ((picks up DT+PL))            ((pakt DT+PL))
          ((coughs)) (1.9)              ((kucht)) (1,9)
          °let's just see°              °even kijken°
          well you write eh:            nou u schrijft eh:
          down that you: are a bit      op dat u: wat
          fearful and                   angstig bent en
```

---

[40] For a more elaborate analysis of the Key of consultations, see Chapter 4

```
          eh have [tensions↑           eh [spanningen heeft↑


P2    Pt:         [well yes               [nou ja
          that [goes]                  dat [gaat]
P3    Dr:      [yes ]                      [ja  ]
P4    Pt: together doesn’t it          samen hè
          tension and fear [that]      spanning en angst [dat]
          is how it                    is hoe het
          [feels] kind of              [voelt] zeg maar
P5    Dr:                  [yes ]                         [ja]
          [yes  ]                      [ja   ]
          that is [it too: ]           dat is [het oo:k ]
P6    Pt:         [but that] may in           [maar dat ] kan in
          ((gestures)) principle       ((gebaart)) principe
          have to  do with that        te maken met die
          with that ear  with that     met dat oor met dat
          head                         hoofd
          which to [me] really eh      wat voor [mij] toch wel eh
          (0.3)                        (0,3)
P7    Dr:          [yes]                          [ja]
P8    Pt: is strange [and]             vreemd is [ook]
P9    Dr:            [yes]                         [ja]
P10   Pt: in that sense strange ehm    in die zin vreemd ehm
      (1.3)                            (1,3)
          yes that you are worried     ja dat je je ongerust maakt
          of course that is            natuurlijk dat is
          of course                    natuurlijk
          all that you think (.)       al dat je denkt (.)
          there’s a tumour in me head  er zit een tumor in me hoofd
```

In P1 doctor starts reading the DT+PL and states that patient has indicated that he suffers from fear and tension. Patient confirms this, commenting that the two go hand in hand (P2, P4), which doctor confirms (P5). Patient then links the physical problems he has with his ear and his head to the anxiety he indicated in the DT+PL ‘But that may in principle have to do with that, with that ear with that head’ (P6). He states that he experiences these problems as ‘strange’, and then in P10 he naturalises the fear and tension he suffers from, by means of ‘of course’. He does this twice in a row: ‘That you are worried *of course*. That is *of course* all that you think, there’s a tumour in me head’. With ‘of course’ patient implies that it is self-evident that a patient should be anxious and tense in the circumstances of having had cancer, and that – since he was treated for a carcinoma on his ear – it is ‘natural’ for him to worry that his ear problems might herald a possible recurrence (see Arora, 2003). If a topic is natural, self-evident, it may not be newsworthy and therefore not topicalisable (see, e.g., Button & Casey, 1984) or mentionable (Schegloff & Sacks, 1984/1973), which might be a reason why patient has not raised these worries before. At the same time, he may simply have been reluctant to discuss emotional problems with his surgeon, considering this outside her brief (see, e.g., Arora, 2003; Beach et al., 2005; Biddle et al., 2016; Heritage & Robinson, 2006a). The DT+PL has created the opportunity to communicate and emphasise the *negative* experience of a 'natural' fear.

An elaborated version of Data 15 shows that the new Instrumentality DT+PL may also function to create a *positive* Key, with a focus on wellness.

Data 15 (elaborated)
Dr D

[Patient's DT score is 0; no items crossed on PL. Data from opening of consultation. Patient has taken the DT+PL from her bag and put it in front of the doctor on his desk]

P1	Dr:	(0.9) ((picks up the DT+PL and looks at Pt)) kijk ((waves DT+PL back and forth)) ((joking tone)) I also don't have to ask you how you are doing because eh:	(0,9) ((pakt de DT+PL en kijkt Pt aan)) kijk ((beweegt DT+PL heen en weer)) ((grappende toon)) ik hoef ook niet meer te vragen hoe het met u gaat want eh:
P2	Pt:	yeahh	jahh
P3	Dr:	you have °filled° this out already ((holds up DT+PL)) ((all smile broadly)) (.)	u heeft dit al inge°vuld° ((houdt DT+PL omhoog)) ((alle glimlachen breed)) (.)
P4	Pt:	yeahh yes↑ [well we'll be finished quickly↑ [((smiling broadly))	jahh ja↑ [nou zijn we gauw klaar↑ [((breed glimlachend))
P5	Dr:	°yes eh uh°((reading DT+PL and nodding)) (0.7) yes we will indeed be finished quickly [((puts down DT+PL and puts his hands on it)) (.)	°ja eh uh°((DT+PL lezend en knikkend)) (0,7) ja we zijn inderdaad gauw klaar [((legt DT+PL neer en legt handen erop)) (.)
P6	Pt:	[hHhh ((exhales))	[hHhh ((uitademing))
P7	Dr:	yes ((looks at Pt smilingly))	ja ((kijkt Pt glimlachend aan))
P8	Pt:	yes that is all I could ↑ma:ke of it	ja ik kon d'r niks anders van ↑ma:ken
P9	Dr:	yes	ja
P10	Pt:	fortunately (.)	fortunately (.)
		lines left out	
P11	Dr:	how is it with you (.) other than that↑	hoe is het met u (.) verder↑
P12	Pt:	well fine	nou prima
		lines left out	
P13	Dr:	no complaints↑	geen klachten↑

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P14   Pt: no                          nee
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The Key in this data is light from the beginning. In P1-3 Dr D jokes about the impact of the DT+PL on his routine 'How are you?' question, and in P4 PT jokes back, smiling broadly, that this will lead them to finish quickly. Doctor agrees 'yes eh uh°' and then starts reading the DT+PL. In the following interaction the content of the DT+PL is never made explicit, but referred to and responded to almost as if the DT+PL is a separate, independent voice (Instrumentality) in the interaction.

The DT+PL informs doctor that patient is free from complaints (0 on DT, no problems crossed on the PL). This might indicate that there is little to discuss. This inference is reflected in doctor's response to what he has read in the DT+PL: 'yes we will in<u>deed</u> be finished quickly' – there are no problems or complaints to discuss, so the expectation is that the consultation will not take long. Doctor responds to the content of what he has read with a big smile, which would indicate good news, and which links to the jokey mood of the interaction up to this point. In the formulation of his response to the DT+PL doctor refers back to patient's previous utterance that they would be finished quickly with an emphatic 'in<u>deed</u>'. There seems to be no felt need to make explicit what he has read, because both doctor and patient are aware that they now share the information in the DT+PL: patient has filled it out and doctor has read it. Making this information explicit might be considered redundant, i.e. it might constitute a violation of the Maxim of Quantity, where more information is given than is necessary (Grice, 1975). Doctor then concludes his 'interaction' with the DT+PL by putting it down and covering it with his hands.
In P6 patient exhales audibly, which might be interpreted as a sigh of relief or satisfaction, and doctor responds 'yes', and smiles at patient; both are clearly content that patient is doing well. Then patient adds (P8) 'yes there was nothing else I could ↑ma:ke of it'. With this utterance she confirms doctor's implied inference that she is doing OK by implying that there were no concerns that were causing her distress which she could have included in the DT+PL: there was 'nothing else' to report than what is in the DT+PL (i.e. absence of distress). Again, there is no explicit reference to the content of the DT+PL. After doctor's continuer 'yes', patient then comments on these positive implications with 'fortunately'. The absence of distress on the DT+PL has contributed to an optimistic Key, focussing on wellness rather than distress.

Doctor and patient co-construct a sense of satisfaction with the absence of distress reported in the DT+PL, without explicitly referring to it. The DT+PL – a nonvocal Instrumentality – has been deemed to communicate its message sufficiently without that message needing vocal repetition.

The doctors in the interviews indicated that they feared that the consultations would turn into a cesspool of problems, thus affecting the Key. But the data show that – just as in the Control group – the Key is mixed. The interaction in Data 7 shows that the DT+PL affords doctor and patient a way into discussing and emphasising 'natural' psychosocial problems, which might otherwise have remained under the radar. However, as Data 15 shows, the DT+PL can also function as an instrument to generate a positive Key, focussed on wellness instead of distress, by showing unequivocally that patient is doing well.

4.0 Discussion and conclusions

Where Biddle et al. (2016) were able to show many of the effects of the introduction of the DT+PL on the basis of interviews with doctors and patients, they were faced with problems of recall, due to the fact that the interviews were conducted 13 months after the administration of the DT+PL. They were also – through their reliance on meta-data – unable to show the impact of the introduction of the DT+PL on daily practice, i.e. on the discursive construction of the consultations by doctors and patients. This chapter shows that it is important to not just trace the ideas and reflections of doctors and patients on the impact of the DT+PL on doctor-patient discourse, but also analyse the actual doctor-patient interactions during the consultations.

The current chapter largely confirms Biddle et al.'s findings with respect to the types of issues involved, but in addition highlights a number of interactional dilemmas and complications for the participants in the communicative event itself. These are related to the goals of the encounter (Ends), doctor-patient role relations (Participants), the routine enactment of the speech event (Act sequence) and to the institutionally required time limits of the consultation (Setting). The doctors in the data used different strategies to negotiate these – sometimes conflicting – demands during the actual consultations.[41]

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[41] Although our small data-set makes it impossible to come to generalisable conclusions, it can be noted that the use of the DT+PL consultations does not seem to have led to greater patient satisfaction in the current data-set. Patients rated their consultations in their post-consultation interviews. Dr A's average scores with and without the DT+PL are identical (8.75), and Dr D's scores average 8.8 for the Control group and 8.1 for the DT+PL group. In neither case has the use of the DT+PL led to a higher patient-satisfaction score while in fact Dr D's DT+PL scores are lower than his Control group scores, although they remain high.

In spite of her concerns about the institutional time constraints, Dr A decided to preserve her normal routine (see Data 13) and to first go through the 'default' Act sequence of her routine follow-up consultation and only then to discuss the DT+PL point by point, using it as a checklist for the anamnesis. This resulted in the discussion of the DT+PL being 'extra', leading to lengthy sessions – the length exacerbated by the large problem load of her patients – and at times to addressing the same problems twice. However, this approach also led to her finding out new patient concerns and problems which otherwise might not have surfaced (Data 7 and 14). In these instances the DT+PL created the affordances for the discussion of these problems.

The risk of repetition and lack of time were problems Dr D had envisaged during the training session (see Data 12). He solved them in the consultations themselves by focussing on *new* complaints, asking his patients to select one or more topics for discussion from the DT+PL as is illustrated in Data 8 and Data 15. This strategy had an unexpected, extra benefit: it led to the discussion of a complaint that had not been mentioned on the DT+PL. This emphasises that the instrument, though useful in uncovering hitherto hidden complaints, cannot be trusted to supply all information necessary for a full assessment of a patient's condition (see also Biddle et al., 2016; Higginson & Carr, 2001).

The data show that the DT+PL was indeed successful in creating the *affordances* for the discussion of psychosocial and other problems. However, it might also *constrain* the topics on the agenda to those issues that are mentioned on the PL – if not used carefully. The doctors in the study show awareness of this by first (or also) going through their 'normal', routine anamnesis, and/or by asking targeted questions to elicit further problems.

Chapter 6: Discussing psychosocial distress in follow-up cancer consultations, with and without the Distress Thermometer and Problem List

1.0 Introduction

The previous chapter discussed the influence of the DT+PL on various contextual parameters of the consultations, the dilemmas it introduces for the participants, and its effects on the selection and discussion of topics. It also showed that the DT+PL constructs relevance for – and indeed invites – the discussion of the problems indicated on the PL, but that, at the same time, it might be construed as ‘constraining’ the topics of discussion: it does not invite the discussion of other problems than those that appear on the PL. In spite of this, problems that appear on the PL are not always discussed, and problems that do not appear on the DT+PL are regularly introduced and discussed in the consultations.

This chapter will revisit the outcomes of previous research that report that the integration into the consultation of patient-related outcome measures (PROMs) in general, and the DT+PL in particular seem to result in more discussion and awareness of health-related quality-of-life (HRQL) issues, but do not result in the discussion of *all* patients’ psychosocial problems (see e.g., Detmar et al., 2002; Van Nuenen et al., 2017; Velikova et al., 2004). Why would that be? In order to find an answer to this question this chapter will first report on the problems that patients indicate they have, and the problems that are addressed in the consultations. It will then focus on how doctors and patients discursively construct the discussion of particular issues. The aim is to shed light on what might cause some problems to be discussed and some to be left out of discussion, and whether or not – and if so, how – that is related to the DT+PL.

Data will be compared from 28 follow-up cancer consultations conducted by Dr A and Dr D (15 in the Control group without the DT+PL, and 13 in the DT+PL group). The video-recordings of the interactional data will be triangulated with data from interviews with both doctors and patients, data from a training-session for physicians on the use of the DT+PL, and the patients’ filled out DT+PLs (see Chapter 1).

2.0 Results

2.1 Overview of problems noted on PL and addressed

Types of problems noted on the PL

Although the introduction of the DT+PL into the follow-up consultation explicitly aims to promote the discussion of *psychosocial* distress, the tool was originally designed to capture a wide array of problems, both physical (25 questions) and non-physical/psychosocial (22 questions, 10 of which are emotional).

Table 1 shows that in the Control group 71 out of 117 issues that patients indicated on the PL (60.7%) were physical against 100 out of 141 (70.9%) in the DT+PL group. Of the psychosocial complaints indicated on the PL, the majority of the problems are emotional, as categorised in the DT+PL (emotional control, memory, self-confidence, fears, depression/feeling down, tension, loneliness, concentration, feelings of guilt, loss of control): 34 out of 46 = 73.9% in the Control group, and 28 out of 41 = 68.3% in the DT+PL group.

	Both groups combined (28 consultations)			Control group (15 consultations)			DT+PL group (13 consultations)		
	Total	Dr A	Dr D	Total	Dr A	Dr D	Total	Dr A	Dr D
Physical complaints	171 (66.3%)	122	49	71 (60.7%)	51	20	100 (71%)	71	29
Psychosocial complaints	87 (33.7%)	61	26	46 (39.3%)	26	20	41 (29%)	36	5
Total	258 (100 %)	183	75	117 (100%)	77	40	141 (100%)	107	34
	Total	Dr A	Dr D	Total	Dr A	Dr D	Total	Dr A	Dr D
Psychosocial complaints: emotional	62 (24.0%)	43	19	34 (29.0%)	19	15	28 (19.8%)	25	4
Psychosocial complaints: other	25 (9.7%)	18	7	12 (10.3%)	7	5	13 (9.2%)	11	1

Table 1 Number of different complaints indicated on Problem List

Note that emotional problems are the most numerous of the psychosocial complaints, making up 24% of all the problems indicated on the PL, and 71% of all psychosocial complaints patients indicated.

Problems addressed

Both in the Control group and in the DT+PL group, there is a discrepancy between the number of items ticked on the PL and the number of items that were addressed (see also e.g., Valikodath et al., 2017). Table 2 shows that, on average, in the Control group a smaller percentage of the problems the patients listed was addressed in the consultation than in the DT+PL group, 22.2% versus 47.5%.[42] [43] [44]

Dr A Control group					**Dr D Control group**				
Patient	DT	PL/E/O crossed	PL/E/O mentioned	Not in PL	Patient	DT	PL/E/O crossed	PL/E/O mentioned	Not in PL
1	-	1/0/0	3/0/0	1	1	6	20/7/1	4/3/0	2
2	0	7/2/2	-	2	2	4	0	-	1
3	3	8/2/1	-	2	3	4/5	10/4/1	4/1/1	3
4	4	3/0/0	1/0/0		4	2	1/1/0	4/0/0	-
5	0	3/0/1	3/0/0	1[2]	5	1	6/3/1	1/1/0	1
6	7	23/7/2	2/1/0	1	6	0	3/0/2	-	-
7	5	9/3/0	-	4					
8	-	18/4/1	2/0/0	2					
9	7	5/1/0	2/0/0	1					
Total 9	3> 4	77/19/7	13/1/0	14	6	2> 4	40/15/5	13/5/1	7

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[42] Note, that in some cases patients did not fill out items on the PL that nevertheless did get addressed in the consultation.

[43] Cf. Van Nuenen et al. (2019) who report that in their DT+PL consultations 75% of the items patients indicated on the PL were discussed with the patients.

[44] In both the Control group and in the DT+PL group there are a number of extreme examples of this discrepancy: in the Control group, four patients crossed between 10 and 23 items on the PL, of which only between one and four were discussed during the consultation. Similarly, in the DT+PL group, four patients crossed between 10 and 25 items on the PL, of which between two and nine items were discussed.

Dr A DT+PL group					**Dr D DT+PL group**				
Patient	DT	PL/E/O crossed	PL/E/O mentioned	Not in PL	Patient	DT	PL/E/O crossed	PL/E/O mentioned	Not in PL
DT+PL 1	5	13/1/0	15/2/0	4	DT+PL 1	5	7+4/1/1	2/1/0	2
DT+PL 2	0	1/0/0	1/0/0	2	DT+PL 2	0	2/0/0	-	1
DT+PL 3	6	6/2/0	6/2/0	1	DT+PL 3	3	12/3/0	6/2/0	1
DT+PL 4	8	19/6/1	2/0/0	2	DT+PL 4	0	0	-	-
DT+PL 5	9	12/3/2	11/1/1	6	DT+PL 5	8	10/0/1	2/0/0	-
DT+PL 6	3	2/0/2	3/0/2	2					
DT+PL 7	8	28/5/2	10/1/3	7					
DT+PL 8	7.5	25/7/4	9/3/1	2					
Total 8	6> 4	106/24/ 11	57/9/7	26	5	2 > 4	35/4/2	10/3/0	4
Total Dr A 17	*9> 4*	*183/43/ 18*	*70/10/7*	*40*	*Total Dr D 11*	*4> 4*	*75/19/7*	*23/8/1*	*11*

DT= Score on Distress Thermometer
PL = Number of items crossed on Problem List
/E = Number of emotional items crossed on Problem List
/O = Number of other psychosocial items crossed on Problem List
PL/E/O Mentioned = Number of problems / emotional problems / other psychosocial problems on Problem List that were nominated in consultation
Not in PL = Number of problems outside Problem List nominated in consultation
*>4 = * number of patients who score higher than 4 on the Distress Thermometer

Table 2 Issues indicated in DT+PL and issues mentioned in the consultation

Note, however, the difference between the consultations of the two doctors, both in the number of problems crossed by their patients (Control group, Dr A 77 vs. Dr D 40 and DT+PL group, Dr A 106 vs Dr D 35), and the percentage of problems addressed in both conditions. In the Dr A's Control group 16.9% of the problems on the PL were addressed, versus 32.5% in Dr D's Control group. In Dr A's DT+PL group 53.8% of the problems on the PL were addressed, versus 28.6% in Dr D's DT+PL group.

Table 3 illustrates what percentage of problems listed on the Problem List is nominated (i.e. introduced as a possible topic of discussion) per type of problem. In the DT+PL group as a whole, a much larger percentage of both physical (+21.2%) and emotional (+25.2%) and other psychosocial problems (+ 45.5%) listed on the PL is nominated than in the Control group. Note again, however, the differences between the physicians.

	Control group			DT+PL group			Difference between Control group and DT+PL group		
	Total	Dr A	Dr D	Total	Dr A	Dr D	Total	Dr A	Dr D
Physical problems listed and nominated	19/71 (26.8%)	12/51 (23.5%)	7/20 (35%)	48/100 (48%)	41/71 (58%)	7/29 (24%)	+ 21.2%	+34.5%	- 11%
Emotional problems listed and nominated	6/34 (17.6%)	1/19 (5%)	5/15 (33.3%)	12/28 (42.8%)	9/24 (37.5%)	3/4 (75%)	+ 25.2%	+32.5%	+41.7%
Other psycho-social problems listed and nominated	1/12 (8.3%)	0/7 (0%)	1/5 (20%)	7/13 (53.8%)	7/11 (63.6%)	0/2 (0%)	+ 45.5%	+63.6%	-20%
Total problems listed and nominated	26/117 (22.2%)	13/77 (16.9%)	13/40 (32.5%)	67/141 (47.5%)	57/106 (53.8%)	10/35 (28.6%)	+ 25.3%	+36.9%	- 3.9%

Table 3 Comparison of types of problems on PL and nominated

Apart from problems indicated in the PL, patients also introduced other problems into the conversation. This stands to reason, since, as Higginson & Carr (2001) state “quality-of-life measures will never capture all aspects of life that are important to an individual” (p. 1297), and patients are likely to suffer from other problems than those mentioned in the PL. In the Control group, patients introduced 21 complaints that were *not* mentioned in the PL (Dr A 14, Dr D 7), ranging from co-morbidity issues (e.g., COPD and diabetes) to after-effects of the malignancy and its treatment (e.g., radiation-induced swollen throat and itchy skin). Of the 21 complaints outside the PL, two problems were related to fear of recurrence (a small lump; ‘swollen things’ in the throat). Patients in the DT+PL group raised 30 problems that were not mentioned in the PL (Dr A 26, Dr D 4): co-morbidity issues (e.g., lung cancer and Parkinson’s), after-effects, side-effects of medication and personal problems (e.g., death of mother, and communication issues between hospitals). Of the 30 problems outside the PL, two (feeling 'something' under the skin in the throat; pressure in left ear) were related to fear of recurrence. In total – Control group and DT+PL group taken together – more than a third of the problems discussed in the consultation (51/144) were not indicated by patients on the PL.[45] This confirms that the PL is not a complete, exhaustive list of what may be the concerns of a head-and-neck-cancer patient (cf. Higginson & Carr, 2001); it shows that other problems may be more pressing than the concerns listed there; and it shows that the DT+PL does not constrain patients in the DT+PL group to focus only on what is on the list (see also Chapter 5).

To sum up this part of the analysis, in the DT+PL group there was an increase in the percentage of problems on the PL that was addressed as well as an increase in the total number of issues that were addressed (both physical and psychosocial). This matches earlier findings (Detmar et al., 2000; Van Nuenen et al., 2017; Velikova et al., 2004). In both groups, however, there are various discrepancies between what patients indicate on the PL and what is discussed during the consultation. On the one hand, more concerns are discussed than are on the PL because patients nominate problems as topics for discussion that do not occur on the PL: this amounts to about 35% of the problems discussed during the consultations. On the other hand, fewer items are discussed than appear on the PL: in the Control group, 77.8% of the problems that patients (later) list on the PL are neither nominated nor discussed; in the DT+PL group this amounts to 52.5%. Note, however, that there are distinct differences between the two physicians: the gap between what is noted on the PL and what is addressed in the consultations in the DT+PL group averages 46.2% for Dr A, and 71.4% for Dr D. Section 2.2 focusses on possible explanations for these discrepancies.

2.2 Possible explanations for the discrepancies

To find possible explanations for the discrepancies in frequency between what is indicated in the PL and what is nominated and discussed in the actual interactional encounter, an analysis was conducted of the interactional data from the consultations themselves, and the meta-data from the interviews and the training session. A qualitative analysis of these data identified four parameters that could have impacted the course of events: one is contextual, two are interactional and one hinges on the design of the PL itself.

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[45] Interestingly, patients did not use the option to fill out such issues under 'Other problems' on the DT+PL.

Contextual parameter: time

Time is one of the parameters that influence the difference between what is noted on the PL and what is discussed. As noted in Chapter 2, in the hospital under investigation doctors are typically allocated 10 to 15 minutes to conduct the follow-up consultation. During the training session, the doctors expressed an acute awareness of these time limitations and their effect on what can be discussed, arguing that the extra issues that the introduction of the tool may raise cannot be accommodated (see Data 1 and Chapter 5, section 3.3).

Data 1[46]
Training session

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Dr D: if you have to engage with this […], there is very little time
already, and this will cost a lot of time, one way or another.
Dr A: it all costs money and time, and that is simply not available.
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The video-data of the consultations show that this time constraint can be problematic: in some consultations there were so many problems on the PL that it was virtually impossible to discuss them all. In one consultation, for instance, doctor and patient discuss a raft of side-effects patient is experiencing from her many different forms of medication, which together cause patient so much distress that she is losing the will to live. It takes the participants more than 50 minutes to discuss 11 out of a total of 12 issues patient indicated on the PL, and to arrive at a plan to tackle her problems.

Interactional parameters

The way in which the DT+PL itself is interactionally introduced by the physician during the consultation may also influence whether all the elements on the PL are discussed or not. In a number of instances, doctors *discursively limit* the number of items on the PL that can be discussed. In three of his five DT+PL consultations, Dr D, after reading the DT+PL, immediately limits the number of 'mentionables' (topics that qualify as suitable/relevant for discussion; Schegloff & Sacks, 1984/1973) by asking a variation of 'are there also (.) eh: <u>things</u> that really have changed↑'. The formulation of this question makes relevant as a possible response only those issues that have changed since the previous consultation, and so are new, not having been discussed before (see e.g., Chapter 5, Data 8).

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[46] Repeated from Chapter 5, section 3.3

Dr A uses a similar discursive device to limit the discussion of a long list of problems later in the consultation, when Anamnesis is well under way, as can be seen in Data 2. Patient has indicated 8 on the DT, which translates as extreme distress, and crossed 28 items on the PL, of which 5 are emotional.

Data 2
Dr A

P1	Pt:	was knackered (.) and now it is [a little bit better because]	was kapot (.) en nu gaat het [weer een beetje want]
P2	Dr:	[now it is a little better]	[nu gaat het weer een beetje]
P3	Pt:	tomorrow I have to [eh]	moet morgen [eh]
P4	Dr:	[yes]	[ja]
P3	Pt:	just try to get back to work	gewoon proberen te gaan werken
P4	Dr:	hHh what would you want most ((puts hand on DT+PL and looks at it)) what would you (.) if-if you could choose and money is not a problem as a matter of speaking right that’s a bit unfair because it always does but hHh what would you want the (.)the most of-of everything that’s on this list want the most (.) to be-be solved first↑ let me put it [this] way	hHh wat zou u het liefste willen? ((legt hand op DT+PL en kijkt ernaar)) wat zou u (.) als-als u mocht kiezen en geld speelt geen rol bij wijze van spreken hè is een beetje flauw want dat doet het altijd wel maar hHh wat zou u het (.) het liefste van-van alles wat hier staat het liefste (.) het eerst verholpen willen hebbe-hebben↑ laat ik het [zo] zeggen
P5	Pt:	[yes]	[ja]
P6	Dr:	[is that the men-]	[is dat de men-]
P7	Pt:	[the tire- the] tiredness	[de vermoe- de] vermoeidheid

Doctor and patient have been discussing the many issues patient has noted on the DT+PL, ranging from physical problems like tiredness, ear-ache and thyroid problems, to miscommunication with the rehabilitation staff and problems with health insurance. Patient has just finished relating how the recent death of his mother has exhausted him, both physically and mentally; through sheer tiredness he no longer has the resilience to deal with emotional stress. In P1 he states that things are a little bit better now; he will go back to work. Although there are still many more issues on the PL that have not been discussed, doctor now focusses the discussion on what is the most important issue for the patient (P4): 'but hHh what would you want the (.) the most of-of everything that's on this list want the most (.) to be-be solved first↑', She thus limits further discussion to patient's most pressing problems and how she can best help him. She then starts specifying a possible answer: 'is that the men-', but patient immediately interrupts with his answer: 'the tire- the tiredness', which has now been co-constructed as the focus for discussion.

Patients, in their turn, can take a leading role in selecting what topics are addressed in the actual consultation; for instance they may choose to *raise a topic depending on whether or not they consider it urgent enough* ('doctorable'; Heritage & Robinson, 2006a). In one of the Control group consultations patient ticked 23 problems in the PL after the consultation, seven of which were emotional (emotional control, memory, self-confidence, fears, depression, concentration, guilt). However, during the consultation he nominated only the items he had put on the list of 'things to discuss with the doctor' that he brought with him: pain and fear, more specifically fear of recurrence. In the interview that took place after the consultation, both the patient and his companion indicated that patient had been able to discuss everything he wanted to discuss. This might mean that the preselection of items to discuss with the doctor which patient had conducted at home when preparing his own list was a better indicator of what he wanted to discuss than the list of items resulting from filling out the PL; the latter items were prompted by the list, rather than intrinsic to his experience.

The fact that Dr A addresses a larger number of issues than Dr D may have a number of causes (see Chapter 5). The first is that her patients simply have a higher problem load. The second is that she tends to go through the PL item by item, touching on a much larger number of issues than Dr D, who has a more holistic approach to the discussion of the PL.

Design parameters of the DT+PL

Finally, the design of the DT+PL itself also weighs in on the course of events. This was an issue that the doctors discussed in the training session for the use of it. One of its main weaknesses, they concluded, is that there is no filter built in to 'weed out' problems that are not cancer-related, fossilised problems that have been discussed and treated before, or problems that the patient does not need/want help with. The DT+PL thus affords patients a possibility to simply ‘vent’, and include issues that are not central to the aims of the follow-up cancer consultation.

In a DT+PL consultation, patient’s companion addressed this problem (Data 3).

Data 3
Dr D

P1	Cp:	because that is the ↑difficulty there are of course a couple of things also related to(.) Parkinson’s disease	want dat is de ↑moeilijkheid d'r zijn natuurlijk een paar zaken ook verbonden aan (.) de ziekte van Parkinson
P2	Dr:	yes	ja
P3	Cp:	so [that is]eh:: then we are like yes do you have to	dus [dat is]eh:: dan hebben we zoiets van ja moet je dat
P4	Dr:	[yes yes yes]	[jaja ja]
P5	Cp:	put it in yes or no ((laughing)) .hh	invullen ja of nee ((lachend)) .hh
P6	Dr:	yes	ja

Companion indicates that they had encountered difficulties filling out the PL, because of co-morbidity issues (P1): ‘there are of course a couple of things also related to (.) Parkinson’s disease’. This made it hard for patient and companion to decide whether or not to indicate these problems on the PL (P3, P5), let alone discuss them in this unambiguously cancer-related consultation. Doctor expresses strong recognition of this dilemma (‘yes yes yes’), even before companion has finished formulating it (Müller, 1996). That patient and companion are not certain of the relevance of such ‘other problems’ for discussion (cf. Sacks 1975) in this setting may be another reason for the discrepancy between what is on the PL and what gets discussed: patients may only choose to raise a problem if *this* doctor at *this* point in time is the right person to discuss it with (Maguire, 2002; Sacks, 1975).

The fact that the PL does not distinguish between cancer-related issues and issues that are not cancer- related, and that problems may end up on the PL that have nothing to do with cancer was also an issue that the doctors discussed in the training session for the use of the DT+PL (see Data 4).

Data 4

Training session in the use of the DT+PL

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Dr A:          if something is related to oncology – there is no
               discussion about that – that is very clear that it
               belongs with us. That is not the point. The point is,
               is everything that surfaces here related to oncology
               and that is quite tricky, really […]
Trainer:       […] or do a lot of things surface which more or
               less accidentally
Dr A:          which […] are issues this person has anyway.
```

Like patient and companion in Data 2, the doctor in Data 3 seems to depart from the presupposition that cancer-related issues are 'legitimate' topics of discussion in the consultation and that non-cancer-related issues are not, or less so. And both doctors and patients consider the possibility of 'contamination' by non-cancer related topics a problematic characteristic of the PL.

The discrepancy between the affordances of the design of the DT+PL and the perceived relevance of an issue for the follow-up cancer consultation may therefore also be one of the factors that cause the discrepancy between what is indicated on the DT+PL and what is discussed in the consultation.

3.0 Discussion and conclusion

In The Netherlands, the DT+PL is widely promoted as a tool to stimulate the discussion of psychosocial distress in follow-up cancer care (cf. Integraal Kankercentrum Nederland 2010; Van Nuenen et al., 2017; Van Nuenen et al., 2018; Van Nuenen et al., 2019). In the dataset this paper draws on the DT+PL seems to be fulfilling this function, at least in terms of the *frequency* with which emotional distress is nominated and discussed: with both doctors, emotional issues are nominated relatively more frequently in the DT+PL group than in the Control group, and a larger percentage of patients' emotional problems is in fact addressed (see Table 3). Also, the discrepancy between the number of problems listed on the PL and the problems that were actually addressed during the consultation was smaller in the DT+PL group (52.5%) than in the Control group (77.8%) (see Table 3).

The increased numbers may have various causes. First, they could partly be the result of the intervention itself or the fact that participants were being observed (Hawthorne effect; Sedgwick & Greenwood, 2015; Observer's paradox; Labov, 2006). Secondly, patients in the DT+PL group filled out the DT+PL just before they met the doctor, which could have primed them to focus on problems, and influenced them into mentioning these problems during the consultation. Thirdly, for the DT+PL consultations the doctors had been instructed to discuss the DT+PL with the patients. The items patients 'pre-nominated' on the Problem List can thus be seen as having been put on the 'agenda' of the consultation, which created the affordances for both patients and doctors to claim relevance for an issue as topicalisable by referring to the DT+PL.

We may conclude that the simple fact that the tool seems to stimulate the discussion of psychosocial issues in follow-up cancer consultations is a point in its favour. It is important to note, however, that there is no complete match between what patients put on the DT+PL and what they wish to discuss. Often patients raise issues in the consultation that they did not indicate on the DT+PL but which they still deem important, and sometimes they indicate problems on the DT+PL which are not cancer-related or urgent, and that they do not wish to discuss. It is striking in this respect that although in the DT+PL group significantly more problems were discussed overall – both psychosocial and physical – still a large number of the items ticked on the PL remained unaddressed. This chapter identified a number of parameters that could explain this outcome: one contextual (available time), two interactional (topic limitation by doctors and topic selection by patients), and one related to the design of the DT+PL itself (not limited to cancer-related issues). The difference in the number of problems discussed in the Control group and DT+PL group seems to show that – in *purely quantitative* terms – the DT+PL seems to have had a positive effect for Dr A, but not for Dr D. However, this may not be due to the DT+PL. Dr A's patients have a higher problem load than those of Dr D, and Dr A's style of discussing the DT+PL leads to a wider-ranging discussion (see Chapter 5).

Chapter 7: On the discursive negotiation of the discussion of patients' emotional problems in cancer follow-up consultations[47]

1.0 Introduction

The discussion of emotional distress in cancer patients has been researched from various angles, using a variety of methodologies, and focussing on various types of consultations and patient groups. A number of studies focus on whether or not doctors respond to patients' nominating emotional distress, e.g., Beach et al. (2005), in a conversation analytical (CA) study of first-time and return visits of melanoma and leukaemia patients, Ford et al. (1996), in a CA study of oncologists giving bad news to cancer patients, and Cameron et al. (2015), developing a taxonomy of compassionate language of oncologists in consultations with patients with advanced cancer. These studies found that doctors tend to "redirect the topic of conversation away from the exploration of emotions" (Cameron et al., 2015, p.1683). In a quantitative study investigating audio-recordings of follow-up head-and-neck cancer consultations on utterance level, Zhou et al. (2015) show that doctors are inclined to reduce space for disclosure of emotional distress if patients initiate this (even if the nomination of the topic is mediated by the use of a quality-of-life tool completed by the patient before the consultation). They will, however, provide space if they themselves elicit the nomination of emotional concerns (see also Finset et al., 2013, Pollak et al., 2007 and Zimmerman et al., 2007). Zhou et al. also propose that *timing* is important: physicians are inclined to 'block' the discussion of emotional issues in the early stages of the consultations, but later in the consultation there is "a time point when consultants started to open up for emotional disclosure" (2015, p. 2479). They quantify this time slot at around six minutes into the consultation. At that moment the difference between the space allotted by doctors to the discussion of emotional distress is at its peak, only to decrease again later in the consultation. In summary, earlier research,

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[47] This chapter is an adapted version of Van der Laaken, M. & Bannink, A. (in press). De discursieve constructie van emotionele problemen in het follow-up consult van hoofd-hals-kankerpatiënten, a Dutch article which has been accepted for publication for the special issue on 'expertise and knowledge in medical and care interactions' of *Tijdschrift voor Taalkunde*.

using a variety of analytical approaches, shows that doctors *on average* tend to avoid the discussion of emotional distress, and tend to give more space to its discussion later in the consultation and if they themselves raise the topic.

Chapter 6 of the current study shows that only a small percentage (18%) of patients' emotional problems is discussed in the standard consultations in the data, and that the introduction of the DT+PL resulted in a significant improvement of the number of emotional issues addressed: in consultations making use of this tool 42% of patients' emotional problems were discussed. Chapter 6 also identified possible reasons why not all patients' problems are discussed; they include available time, topic limitation by doctors, topic selection by patients and the design of the DT+PL.

The current chapter focusses on *how* emotional issues are discussed; more specifically, it investigates the following questions:

1. How do doctor and patient employ their epistemic knowledge and experience to discursively construct the (relevance of the) discussion of emotional problems in head-and-neck cancer follow-up consultations?
2. Is there a difference between the standard consultation and consultations using the DT+PL group regarding this issue?

This chapter will make use of the 28 recorded consultations of Dr A and Dr D (15 in the Control group and 13 in the DT+PL group), which will be triangulated with video-recorded interviews with the doctors and their patients, a video-recording of a training session on how to work with the DT+PL, patients' medical data and their filled out DT+PLs.

2.0 Results

2.1 Patterns in the data set

To surface possible patterns relating to what problems are nominated by whom and at what point in the consultation, first a quantitative overview of the interactive data was created. The areas of distress listed in the DT+PL as emotional were the most frequently found psychosocial issues in the data: 18 (69.2%) out of the 26 psychosocial problems discussed in the combined Control group and DT+PL data belong to this category (Chapter 6).

Table 1 below gives an overview of the data set in terms of :

- what type of emotional concerns were nominated;

- by whom they were *first* nominated;
- at what point during the consultation;
- whether nomination resulted in discussion of the concern.

As shown in Table 1, in the Control group there is a wide discrepancy between the emotional problems patients indicate in the DT+PL – filled out *after* the consultation – and the emotional issues that are raised in the consultations.

	Control group; 15 consultations **10 with emotional problems on PL** **4 with emotional problems discussed**		**DT+PL group; 13 consultations** **8 with emotional problems on PL** **7 with emotional problems discussed**	
	concerns *first* nominated by doctor	**concerns *first* nominated by patient or companion**	**concerns *first* nominated by doctor**	**concerns *first* nominated by patient or companion**
Start anamnesis		1 (depression; not discussed)	1 (loneliness; not discussed)	1 (depression due to comorbidity and medication; discussed)
Late anamnesis		1 (death of wife; discussed) 1 (nervous/fear; not discussed until later, after physical examination)	5 (sombreness; fear and tension; fear and depression; discussed) 1 (concentration; discussed)	1 (lacks resilience; discussed)
After physical examination		3 (fear of recurrence; discussed)		2 (fear, memories of anaesthetic; discussed) 1 (sick grandchild; discussed)
	0	6	7	5

Table 1 Overview of the data set

Ten of the 15 patients indicated on the DT+PL that they suffered from emotional distress, but they were addressed in just four of the consultations (see also Chapter 6). In all four consultations, it is the *patient or their companion* who *first* 'nominate', i.e. introduce into the consultation, the emotional problems as a topic for discussion; doctors do not in any of the Control group data of their own accord bring up possible emotional problems or ask after patients' emotional wellbeing.

The situation in the DT+PL group is very different. All in all, eight patients indicated emotional concerns on the PL; in seven consultations these problems were addressed. The topic was nominated by the doctor in four consultations; by patients in three. These results show that in these consultations the DT+PL – as intended – clearly functioned as a tool for 'pre-nomination' of the topic (i.e. to put emotional distress on the agenda for the consultation), making it available as a 'mentionable' (Schegloff & Sacks, 1984/1973) in the interaction that is to follow.

Table 1 shows that in both groups the nomination of emotional problems *in the vast majority of cases* led to discussion (16 out of 18 instances of nomination). Doctors and patients both tended to nominate emotional problems in the later stages of the consultation, during the physical or towards the end of anamnesis. All these issues were then discussed. In three cases, emotional issues were mentioned early in anamnesis. Only one of these three was then discussed.

The sections below will investigate how the nomination of emotional distress is discursively constructed by doctor and patient in the Control group and in the DT+PL group. For both groups one data set is discussed in detail. These two datasets are typical examples of the way in which emotional distress is constructed in the two groups. Where relevant, short quotes from other consultations will be provided, to illustrate the patterns of interaction.

2.2. Qualitative analysis of a Control group consultation

The patient in Data 1 underwent surgery, radiotherapy and chemotherapy of metastasis in the neck of an unknown primary two years before the consultation. She scores high on the DT (6), which translates as problematic distress,[48] and has crossed 20 problems on the PL, seven of which are emotional problems (emotional control, memory, self-confidence, fears, depression, tension and concentration). Since these are data from the Control group, in which the patients filled out the DT+PL *after* the consultation, patient has not been primed to discuss these issues by filling out the form. Neither does the physician have information about these problems at the start of the consultation; he is 'unknowing' (Heritage, 2013) in this respect, and dependent

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[48] For The Netherlands, research indicates that patients scoring 5 or higher on the DT experience problematic distress (see Integraal Kankercentrum Nederland, 2010; Tuinman et al., 2008).

for his information on what patient tells him. We enter the data at the very beginning of anamnesis.

Data 1

Dr D

P1	Dr:	how is it going=	hoe is ‘t ermee=
P2	Pt:	=.hhh (.) Imyself think	=.hhh (.) ikzelf vind
		fine	goed
P3	Dr:	bbu:::t↑	mmaa:::r↑
		(1.0)	(1,0)
P4	Pt:	yes I (.)	ja’k (.)
		((turns head towards Cp))	((draait hoofd richting Cp))
		yes	ja
		((Cp does not respond but	((CP reageert niet maar
		continues to look	blijft kijken
		at Pt throughout))	naar Pt))
		((turns back to Dr))	((draait weer naar Dr))
		(0.2)	(0,2)
		actually was	ben eiglijk depressief
		depressed=	gewees=
P5	Dr:	=yes ((nodding))=	=ja ((knikkend))=
P6	Pt:	=just a coupla weeks	=een pa weken maar
		((Dr nods throughout))	((Dr knikt al luisterend))
		(0.2)	(0,2)
		I’ve managed to put that	’k heb me d’r weer overheen
		behind [me]=	ge[zet]=
P7	Dr:	[yes]((nodding))	[ja] ((knikkend))
P8	Pt:	=so uh	=dus uh
		((Dr nods throughout))	((Dr knikt al luisterend))
		(0.5)	(0,5)
		yes in itself uh (.) it is	ja op zich uh (.) gaat
		going okay=	‘t goed=
		=now and then me voice does	=af en toe valt me stem wel
		break up a little [bu]	een beetje weg [maa]
P9	Dr:	[yes]	[yes]
		((nodding))	((knikkend))

After doctor, patient and companion have entered the consultation room and settled down, doctor kicks off the business at hand of the consultation in P1 with ‘how is it going’. ‘How are you?’ questions such as this (HAY?; Coupland et al., 1994; Frankel, 1995; Heritage & Robinson, 2006b; Rogers & Todd, 2010) are typical for the openings of anamnesis in the Control group, occurring in 14 out of the 15 consultations (see Chapter 3). It is an open question, which gives patient the possibility to report positive as well as negative health outcomes. It also establishes the medical context of the interaction, focussing as it does both on the ‘topical agenda’ of this stage of the consultation – patient’s current state of being – and on the ‘action agenda’ – inviting patient to give an assessment of her current state of being (Boyd & Heritage, 2006).

In spite of the many problems she would indicate on the PL after the consultation, patient initially responds to doctor's HAY? question with an orientation towards wellness with 'fine', a holistic positive gloss, which is found in the majority of the data of the current study (88.9%; see Chapter 3). Her reply, however, is delayed with 'hhh', and a micropause, and hedged with 'I myself think', with emphasis on 'self', limiting the scope of 'fine'. This combination of discourse markers indicates a complex response (Mazeland, 2016) and functions as a trouble premonitor (Jefferson, 1980). Doctor picks up on the implicit cues qualifying patient's positive response with a questioning 'bbu:::t↑' (Dutch *maar*), which indicates a contrast, an alternative option (Umbach, 2004). Here it signals that doctor recognises and acknowledges the complex nature of patient's response: he suspects there is more to be heard, which contrasts with 'fine'. It explicitly invites patient to elaborate.

In P4 patient provides an account for her hedged reply. Making eye-contact with companion (who has been looking at her since P2, and continues to look at her), she again provides a delayed response with two fillers and a short pause 'yes I (.) yes', which may indicate troubles resistance (Heritage & Robinson, 2006a; Jefferson, 1988). She turns her head back at doctor and after a short pause discloses that she 'actually was depressed'. The use of the discourse marker *eigenlijk* ('actually') indicates that the content of the utterance might be unexpected after the first positive response (Van Bergen & Bosker, 2018). The tense – Dutch present perfect *ben geweest* – communicates that this depression is situated in the past, and so is over now. Doctor latches a minimal response immediately after patient's disclosure (P5), inviting patient to continue and providing extra interactional space, allowing patient a prolonged, story-type turn (Schegloff, 1982; see also Frankel, 1984; Finset et al., 2013). Patient continues in P6 and minimises her problem by claiming it was of only short duration: 'just a couple weeks', and indicating she has actively worked to solve it, 'I've managed to put that behind me'. Patient here displays strong trouble resistance, i.e. a 'display that patients are currently coping with their problems with fortitude' (Heritage & Robinson, 2006a, p. 76) and are trying hard to get out of their sick role (Parsons, 1951, Parsons, 1975). In P8 patient then rounds off her story – signalled by the discourse marker 'so', indicating an approaching topic shift (Redeker, 2006; cf. 'coda', return to the present, Labov, 2010) – with '=so uh (0.5) yes in itself uh (.) it is going okay='. Again, the message that she is doing okay is heavily hedged with delay *uh* (twice); pause (twice); and 'in itself', resulting in a very tentative orientation to overall wellness. Doctor has listened attentively throughout patient's account of her depression, providing a continuer (P7: ‘yes’), and nodding (P8), thus inviting patient to continue, but neither commenting on patient’s account nor asking for elaboration.

Patient now immediately changes topic and focusses on a biomedical problem, ‘=now and then me voice does break up a little bu’. Patient creates a contrast with her previous holistic assessment of ‘okay’ with the Dutch discourse marker ‘wel’ in ‘valt *wel* weg’, rendered here as ‘*does* break up’. However, the nomination of the problem with her voice is minimised both in terms of time (‘now and then’) and in strength (‘a little’), so patient simultaneously performs a ‘troubles-telling’, and ‘troubles resistance’ (see Jefferson, 1988). Doctor again provides a continuer (P9), in overlap with patient’s ‘bu’, giving her the opportunity to continue her account of her condition, which now focusses on the biomedical.

To sum up, in a complex extended response to doctor’s ‘How are you?’ question at the start of anamnesis, patient nominates her depression as a possible topic, downplaying it quite strongly in the same turn: she brackets her emotional concern between claims of wellness (P2 and P8); claims the depression was of short duration (P6); and states that she has got over it (P6). Throughout her extended turn at talk doctor encourages disclosure by nodding continuously and by acknowledging what she says with the continuer ‘yes’ (P5 and P7). This interactional behaviour matches findings in Finset et al. (2013), who show that doctors tend to give room for disclosure to the first concern patients raise. Doctor, however, does not ask follow-up questions probing the issue more deeply at this early stage of the consultation, and patient herself rounds off in P8 with a – tentative – overall positive assessment of her emotional situation and a change of topic to physical problems. It may be concluded then that patient and doctor have together, discursively, constructed patient’s bout of depression as a mentionable at this stage of the consultation and as worth interactional space but also as unsuitable for further elaboration at this moment (cf. Zhou et al., 2015).

At the post-consultation interview with this patient, it becomes clear that the depression was, in fact, related to fear of recurrence. When probed about the nature of her depression, patient related that she had been anxious about possible recurrence a few weeks before the consultation, because she was worried about what this would mean for her 15-year-old son (see Data 2).

Data 2

Interview Pt Dr D

When treatment is over - well, then you are afraid, the waiting, and has it returned, is it completely gone. Yes and especially moments when you have been speaking a lot and when your voice breaks up, and yes you remain subconsciously and consciously afraid still. Yes it is what it is.

[...]

Yes a few weeks ago I really was a little depressed and I was thinking, what if it has come back, my son, because I still have an underage son at home, who is almost sixteen, and you are, you then start to, well, eh yes -

Patient’s underlying worry about recurrence explicitly surfaces at a later stage in the same consultation, as shown in Data 3. Early in the consultation patient explained that she had recently fallen on her face, with a black eye and tenderness in the nose as a result. We enter Data 3 later on, at the end of anamnesis, just after doctor has announced the next phase of the consultation, the physical examination.

Data 3

[Same patient and same consultation as in Data 1]

```
P1    Pt: I’ve had-u:h (.) really    khebt-u:h (.) ontzettend
          a lot of blood↑            veel bloed↑
P2    Dr: yes=                       ja=
P3    Pt: =.hhhh (.) so uh           =.hhhh (.) dus uh
          I had a little blood in    ik had een beetje bloed in
          me throat <[last]week>=    me keel <af[gelo]pen week>=
P4    Dr:            [yes ]                     [ja  ]
P5    Pt: = but that can only have   =maar dat kan alleen maar van me
          come <from me [nose]>      <neus afgekomen [zijn]>
P6    Dr:               [yes ]                       [ja  ]
          (0.2)                      (0,2)
P7    Pt: [dss]                      [dss]
P8    Dr: [well] we’ll look at       [nou ] gaan we ook
          that too=                  kijken=
          ((softly))I °think         ((zacht))ik °denk ’t
          for sure it is yes°(0.2)   zeker ja° (0,2)
          ((Dr turns his chair       ((Dr draait zijn stoel richting
          towards examination        de onderzoeks-
          chair))                    stoel))
P9    Pt: ((takes a sip of           ((neemt slok van
          her drink and gets up))    drinken en staat op))
          .mm (.) I am nervous       .mm (.) ik ben zenuwachtig
          you know↑                  hoor↑
          hh.hh                      hh.hh
          (1.0)                      (1,0)
          ((walks towards            ((loopt naar
          examination chair))        onderzoeksstoel))
P10   Dr: ((grins briefly))          ((grinnikt kort))
P11                           Lines left out;
         Physical examination with ‘no problem’ running commentary
                                  by Dr D
```

P12	Dr:	no (.) fine	nee (.) prima
P13	Pt:	hhhhhh. hm ((breathes	hhhhhh. hm ((ademt
		out audibly))	hoorbaar uit))
P14	Dr:	so (0.2) those nerves	dus (0.2) die zenuwen
		(.) can be switched off	(.) kunnen uit
P15	Pt:	indeed=they are too	inderdaad=die vallen ook
		immediately falling	gelijk
		off me	van me af
		hh ha ha .hh	hh ha ha .hh
		(2.0) ((Dr and Pt both	(2,0) ((Dr en Pt gaan beide
		sit down again at Dr's	weer aan
		desk))	Dr's bureau zitten))
		[((deep sigh))	[((diepe zucht))
P16	Dr:	[((starts filling out	[((begint vanaf hier
		patient's file on the	patiëntendossier op computer in
		computer))	te vullen)
		(1.0)	(1,0)
		((Cp looks at Pt))	((Cp kijkt naar Pt))
P17	Pt:	well I was afraid of	na ik was hier bang
		this today you know=	voor vandaag hoor=
P18	Dr:	=yes↑ ((looking at	=ja↑ ((kijkend naar
		screen))	scherm))
P19	Pt:	ye:s totally	ja: echt wel
P20	Dr:	why↑	waarom↑
P21	Pt:	.hh I don't know (.)	.hh ik weet 't niet (.)
		uh (.)	uh (.)
		((Pt looks at Cp)) yes	((Pt kijkt Cp aan)) ja
		[(2.5)	[(2,5)
		[((Pt turns head back	[((Pt draait hoofd weer terug
		looks at the floor))	kijkt naar de vloer))
P22	Cp:	((Cp turns to Dr))	((Cp draait naar Dr))
		.tk you hear it so often	.tk je hoort 't zo vaak
		right that it comes back	hè dat 't toch
		again anyway with people	weer terug komt bij mensen
		(.) [after] two three	(.) [na] twee drie
		years	jaar
		[((Cp looks at desk))	((Cp kijkt naar bureau))
P23	Dr:	[yes] (0.2)	[ja] (0,2)
		we:ll yes m-	nou: ja d-
		(0.2)((stops typing and	(0,2)((stopt met typen en
		looks at Cp))	kijkt Cp aan))
		((Cp and Pt look at Dr))	((Cp en Pt kijken Dr aan))
		th' most with:in two	d' meeste b:innen twee
		years ((nodding))	jaar ((knikkend))
P24	Cp:	yes	ja
P25	Dr:	(0.5)((looks at screen	(0,5) ((kijkt naar scherm
		and back at Cp))	en terug naar Cp))
		[one and a half (.)	[anderhalf (.)
		[((wiggling hands	[((beweegt handen met
		signalling 'more or less')	boodschap 'zo ongeveer'))
		[so if that period b-	[dus a's je die periode b-
		[((Pt and Cp nodding	[((Pt en Cp knikken
		softly))	zachtjes))
		is-has passed [you	voorbij be-heb [heb je
		already have an uh	al 'n uh
		((Dr looks at screen	((Dr kijkt weer naar
		again))	scherm))
P26	Cp:	[(as to-)	[(qua-)
		as to acquaintances they a	qua kennissenkring die zijn d'r

		like uh	zo uh
		(0.2)	(0,2)
		two years (.)	van twee jaar (.)
P27	Dr:	[yes]	[ja]
P28	Cp:	[so] that they were	[dus] dat ze genezen
		cured	waren
		((Dr starts typing again))	((Dr begint weer te typen))
		or were clean and that	althans schoon waren en dat
		they then nevertheless	ze dan toch
		again uh .hhh	weer uh .hhh
		within one and a half	binnen de anderhalf
		two years	twee jaar
		↑had it again	’t weer ↑hadden
		(1.5) ((Dr still	(1,5) ((Dr typt nog
		typing))	steeds))
P29	Pt:	.hhh ((deep sigh))	.hhh ((diepe zucht))
		°well° hhhh	°nou° hhhh
		[((Pt picks up paper and	[((Pt pakt papier van tafel en
		puts it back))	legt het weer terug))
		[(3.0)	[(3,0)
P30	Dr:	((Dr stops typing and	((Dr stopt met typen en
		looks at screen))	kijkt naar scherm))
		but I can’t make	maar ik kan d’r niks
		anything of it now	van brouwen nu
		(.) so uh (0.2)	(.) dus uh (0,2)
		[((Pt takes sip of water))	[((Pt neemt slok water))
		[completely fine	[helemaal goed
		[(10.0)	[(10,0)
		[((continues to fill in	[((vult elektronisch dossier
		electronic file))	verder in))
		[((Pt looks at desk))	[((Pt kijkt naar bureau))
		[((Cp looks at Pt))	[((Cp kijkt naar Pt))
		I’ll just for form’s sake	k-zal alleen nog voor de vorm een
		echo=	echo=
		((Dr looks at screen))	((Dr kijkt naar scherm))
		((Pt and Cp look at Dr))	((Pt en Cp kijken Dr aan))
		=there’s really no	=’t heeft eigenlijk geen
		point but well	zin maar goed
		((Dr looks at Pt, shrugs	((Dr kijkt naar Pt, trekt
		shoulders, nods))	schouders op, knikt))
P31	Pt:	[to be[sure	[voor de zeker[heid
		[((looks at Dr and	[((kijkt Dr aan en
		nods))	knikt))
P32	Dr:	[to be sure yes	[voor de zekerheid j
		((Dr looks back at screen)	((Dr kijkt weer naar scherm))
		(.)	(.)
		w- (.) when do you have	w- (.) wanneer heeft u nu
		a next appointment↑	weer een afspraak↑

In P1 patient mentions that she had blood in her throat the week before, first referring to the incident through extreme language (Pomerantz, 1986) and a lot of emphasis ‘really a lot of blood↑’ to emphasise the gravity of the problem and make it doctorable (Heritage & Robinson, 2006a), but then immediately minimising it to ‘a little blood’, downplaying its severity, in P3 (see also Chapter 4). Blood in the throat may of course be a worrying symptom for a person who has been treated for a tumour in the neck, but patient – again in same turn –

goes on to claim that the blood 'can only have come from me nose' (P7); a lay diagnosis which is less worrying than other possible causes and which stems from patient's personal knowledge of recently having fallen quite badly on her face.

Usually lay diagnoses are formulated quite tentatively so as not to interfere with doctor's task of finding out what – if anything – is wrong with patient (Gill & Maynard, 2006). In this instance, patient's formulation of her lay diagnosis is unusually strong, *de facto* dismissing a potentially worrying symptom, and minimising the quantity of blood in P1. This may be an example of a patient downplaying or denying problems in order to minimise reasons to be concerned (as Beach (2013, p. 579) formulates it, in order to "to talk health [...] into being"). Nevertheless, although patient claims that the bloody nose can only have an innocent explanation (and so is not doctorable), by nominating it she at the same time directs doctor's attention to the problem, so that he might investigate it (see Pomerantz et al., 2007; see also Chapter 6).

Patient's lay diagnosis is formulated as a sequence of 'symptom + explanation', leaving Dr D free to respond to either the first part of the utterance, the symptom, or the second part, the explanation (see Gill, 1998; Gill & Maynard, 2006). Doctor here does both: he responds to the symptom and patient's implied request to have a look at it – '<u>well</u> we'll look at that too' – and he responds to patient's diagnosis '=I °think for sure it is yes°'. Such an evaluation at this phase of the consultation is unusual according to Gill & Maynard (2006); doctors – if they respond to a lay diagnosis at all – tend to do this after the anamnesis and physical examination, when all the relevant information has been gathered. Doctor's meta-comment 'for sure' may indicate certainty. However, the fact that doctor formulates his evaluation in a low voice, and as a 'thought' rather than as a definite conclusion may indicate that he is not altogether committed to it and that his final verdict will depend on the physical examination he has just announced. His complex response may be intended as a preliminary reassurance for the patient (Gill & Maynard, 2006).

In P9, patient for the first time in the consultation nominates anxiety, stating, '.mm (.) I am nervous you know↑' (P9). Although the statement itself is direct, in that patient explicitly names her emotion ('nervous') (Beach & Dozier, 2015), patient does not make explicit what she is nervous about, leaving it to doctor to infer that from the current context, i.e. the start of the physical examination. The mention of nervousness is presented as possibly dispreferred: patient begins the utterance with a hesitation marker and delay, and closes it with *hoor*. The particle *hoor* (here glossed as ‘you know’) often functions as a device to involve the hearer (Kirsner & Deen, 1990).

Doctor acknowledges patient’s nomination of nervousness with a grin, but does not respond to it verbally, nor does he elicit further disclosure. He simply focusses on the next task on the agenda of the consultation, and proceeds with the physical examination (see e.g., Easter & Beach, 2004; Finset et al., 2013). During the examination he gives a running commentary of what he sees and feels, which is all positive (not in transcript).

In P12 doctor sums up his findings with an unmitigated, positive verdict: ‘no (.) fine’, with ‘no’ referencing that he has not found anything problematic, and ‘fine’ referencing patient’s status. In response patient heaves an audible sigh of relief (P13). Only now (P14) does doctor verbally respond to patient’s mention of nerves in P9: ‘so (0.2) those nerves (.) can be switched off’. With a deictic expression explicitly referencing patient’s earlier remark (‘*those* nerves’), this response shows that doctor had been listening closely, even though he did not at first respond verbally, and that he has correctly inferred what patient was nervous about. The response also implies the reason for his delayed response (indicated with the concluding discourse marker ‘so’): the physical examination was a means of ascertaining whether there was a basis for patient’s nervousness; in order to reassure patient, doctor has utilised his medical expertise.

Patient – laughing in relief – responds that the nerves have instantly disappeared, ‘indeed = they are too immediately falling off me hh ha ha .hh’ (P15), using a Dutch idiomatic expression related to ‘that is a weight off my shoulders’. The physical examination, its ‘verdict’ and patient’s acceptance of this have now been completed, and doctor and patient resume their seats at doctor’s desk. Doctor now has all the information he needs and proceeds to fill out patient’s file and wrap up the consultation.[49]

However, in P17 patient reintroduces her fears once again with an unsolicited comment ‘well I was afraid of this today you know=’. Patient formulates her fear directly (‘I was afraid’; Beach & Dozier, 2015), with a deictic reference to

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[49] At the time of recording the hospital had only very recently introduced electronic files, and the doctors in this study are having a hard time getting used to typing up rather than writing down patients’ data. Doctor D frequently refers to this by apologising for the longer duration of filling out the files. In this consultation, too, it takes him a long time to type everything up.

the physical examination ('of this'). She precedes her re-introduction of the topic with Dutch *nou* ('well') – which here functions to indicate the next utterance may be divergent from what is expected (Pander Maat, 1986; Mazeland, 2012)–, and finishes with *hoor* ('you know'), softening the statement (Kirsner & Deen, 1990). This shows patient's awareness of the interactional dispreferredness of returning to the topic she and doctor have just closed (Pander Maat, 1986).

In spite of this, doctor – still looking at the online file he is filling out – responds to this with a question-marked 'yes↑', thus accepting patient's remark, acknowledging her fear and inviting her to elaborate. In P18 patient reconfirms her fears with an emphatic 'ye:s <u>to</u>tally', with stretched out 'ye:s' and strong emphasis on '<u>to</u>tally'. Doctor's response 'why↑' (P19) explicitly invites her to elaborate (cf. Finset et al., 2013). However, rather than explaining the reasons for her fear immediately, in P20 patient hangs back with a lot of hesitation ('.hh') and delay (.), responding '.hh I don't know (.) uh (.)'. She seems reluctant to answer the question and discuss her fears (a well-documented phenomenon; see e.g., Arora, 2003; Heritage & Robinson, 2006b). Instead she shifts her gaze to companion, thus altering the participation framework to include him as an addressed recipient, and therefore as a possible ratified next speaker ('footing'; Goffman, 1979): her gaze is a nonverbal invitation to her companion to take over her turn at talk.

After a long delay (2.5 seconds), during which patient looks at the floor, companion turns to doctor and answers doctor's question in patient's stead (P22), finally naming the pink elephant in the room. The reason for patient's fear turns out to be that patient and companion have been afraid of recurrence: '.tk you hear it so often right that it comes back again anyway with people after two three years'. With 'you hear it so often' companion underpins the fear with knowledge from his own life world, the experiences of other people ('hearsay', Beach et al., 2005; Gill, 1998; Heritage & Robinson, 2006a). The utterance is accompanied by insecurity markers, '.tk', and 'right' (*hè*), inviting agreement. Gill (1998) has shown that "when patients exhibit tentativeness and uncertainty about the knowledge they are displaying in their explanations, they also tentatively invite doctors' assessments" (p. 356), *hoc loco* to assess the truth value of the length of time within which recurrence is likely. But notice that companion does not formulate the fear of recurrence directly, i.e. does not use terms like 'fear' or 'afraid', but implies it (Beach & Dozier, 2015), leaving it to doctor to make the connection.

Doctor's reaction in P23 and P25 is complex. At first he seems to register agreement with companion ('yes'), but he qualifies this after a short pause with 'we:ll yes m-', discourse markers indicating a dispreferred interactional action (Pomerantz, 1984), and a face-threatening act (Brown & Levinson, 1987/1978). He stops typing, makes eye contact and then formulates disagreement with companion, nodding for emphasis, 'th' most with:in two years (0.5)'one and a half (.)', wiggling his hands signalling 'more or less'.

This first part of doctor's attempt to reassure patient and companion is a generic statement indicating 'what usually happens'. Doctor's 18-to-24-month timescale – based on his medical expertise and experience – contradicts companion's 24-36 months. Doctor then tailors this to patient's specific circumstances (cf. Beach & Dozier, 2015) with some disfluency ('b- is-has'): 'so if that period b- is-has passed you already have an uh', not completing his statement but implying that the period of worst risk for patient – who was treated for her malignancy two years before – is over. Doctor then looks at his computer screen again, signalling that the topic is finished as far as he is concerned.

Although patient and companion have nodded their assent, doctor's reassurance does not seem enough to allay their fears. In P26 and P28 companion repeats and further elaborates the 'hearsay': 'acquaintances' experienced recurrence within one-and-a-half to two years after a period of wellness (for cancer fears getting expressed via reports about friends and family, see e.g., Beach et al., 2005). He does so with some disfluency and delay (repeated 'as to', 'like uh', and a pause), which indicates the dispreferredness of returning – yet again – to a topic that doctor clearly thinks is closed. He does, however, now match doctor's time scale: '(as to-) as to acquaintances they are like uh (0.2) two years (.) that they were cured'. While doctor starts typing up patient's file again, companion concludes with 'or were clean and that they then nevertheless again uh .hhh within one and a half two years ↑had it again'. This repetition of the experiences of their acquaintance indicates that this has made a huge impression on patient and companion and has fed their fear of recurrence.

At first doctor does not respond to companion's remark but continues to type up patient's data in the medical file. However, in P30 doctor stops typing, and, still looking at the screen, states that his current 'no problem' diagnosis stands: 'but I can't make anything of it now', with discourse marker *maar* ('but') announcing that doctor has registered what companion has been saying but has not found anything to warrant worry. He re-emphasises this with an explicit conclusion marker ‘so uh’ followed by a pause, leading into the reassuring message ‘completely fine’. All in all, in doctor’s expert opinion patient at this point in time (‘now’) shows no signs of recurrence (whatever the experience of companion’s acquaintance), so the fears companion expressed would seem to be unfounded for the time being.

Patient and companion do not respond and sit waiting for doctor to finish filling out the file for ten seconds. Then, still turned to the screen, doctor starts speaking again. Apparently, he has decided that he should interpret companion’s elaboration as an indication that the fears of patient and companion have not been completely dispelled, even after the positive results of the physical examination, and his reassuring remarks about the critical period having passed. So he announces that he will order extra tests: ‘I’ll just for form’s sake an echo=’, latching on grudgingly ‘=there’s <u>rea</u>lly no point but well’, after which he looks at patient, shrugs his shoulders and nods. The message is clear: the tests are really not necessary, but we’ll do them anyway, to reassure you. Patient accepts this, nodding, commenting ‘just to be sure’, which doctor confirms by recycling her utterance and adding an affirmative ‘just to be sure yes’ (P32).[50]

Finally the discussion of patient’s fears is over: in P32 doctor looks back at the screen and starts the rounding off phase of the consultation, asking patient ‘w-(.)when do you have a next appointment’.

According to e.g., Maguire (2002) doctor’s responses in P10 and P30 would constitute a case of doctor “blocking” the discussion of “feelings and the underlying concerns” (p. 178). In the same vein, Zhou et al. (2015) might have labelled them a ‘reduced space response’[51] in the coding scheme they employed to categorise the participants’ utterances. It can be argued, however, that these characterisations of doctor’s interactional behaviours would not do justice to the interactional work the doctor is doing during this consultation. His responses are fully appropriate to the business at hand in the regular, scheduled follow-up cancer consultation, which is geared primarily to checking for recurrence, and – in the absence of recurrence – taking away patients’

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[50] It would seem that tests – or even the announcement of tests – have even more authority, and as such a greater power to reassure than the doctor’s expertise, which manifested itself in the results of the physical examination and his statistical knowledge about risk of recurrence.

[51] Zhou et al. (2015) would have missed the doctor’s nonverbal cue (his grin) altogether, since their data consisted of audiotapes.

anxiety and fear of recurrence (Chapter 3). The instruments that doctors have at their disposal for this, in their epistemic role of biomedical expert, are physical examination and medical tests. The practical way in which doctor responds to the nervousness about the bleeding and worries about recurrence that patient and companion express in Data 3 – by quickly moving to the physical examination after the anxiety has first been expressed (P8), and ordering extra tests after it has been expressed again (P30) – is in line with this, and matches how Dr D formulates his role in consultations with patients who come in with a complaint that may be related to the recurrence of the disease.[52] In Data 4 Dr D explains that his strategy is to examine them as soon as possible, so that he can take away emotional concerns, such as anxiety.

Data 4
Interview Dr D

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so people who come in eh eh with complaints … and they are of course
actually a bit afraid that the complaints again have to do with the
disease which has come back. There the aim is to reassure those people
as soon as possible. So that means examining them.
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So what doctor does not do, and what he does not *aim* to do in P10, as implied in Data 4, is engage in what is known as 'therapy talk', discourse that is intended to solve mental problems by talking (Weiste & Peräkylä, 2015), or 'troubles talk'/'troubles-telling', in which the troubles-teller shares his/her troubles and receives empathy (Jefferson, 1988; Ten Have, 1989). In his epistemic role as biomedical expert doctor prioritises the main objective of the consultation: monitoring patient's medical state and making sure there is no recurrence of the disease. Only when this has been completed and no abnormalities have been found – and so, in doctor's expert medical opinion, there is at this point in time no need to worry – , does he give patient and companion room to elaborate on their fears (P20). His question explicitly invites patient (and by proxy companion) to tell the story behind patient's anxiety. He then combines listening to companion's narrative with the institutional task of filling in patient's file on the computer.

The post-consultation interview with the patient shows that doctor's interactional strategies to alleviate patient's fears have indeed been successful:

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[52] In their taxonomy, Cameron et al. (2015) list this practical form of reassurance as a way of showing compassion.

Data 5

Interview Pt Dr D

Interviewer:	I was wondering how the consultation went just now
Patient:	Do you see how radiant I am? I am completely radiant
Interviewer:	You have had good news
Patient:	Very good news, yes
Interviewer:	Oh how wonderful
Patient:	So eh yes, nerves for nothing, really eh. It is really as good as gone. Well it is gone, isn't it? […] Well it is just all looking fine. He looked in my nose with a camera and yes just everything is everything is perfect. I have to in (.) eight months?

Patient is, as she herself phrases it, 'radiant' after the consultation, having been nervous 'for nothing', because the physical examination showed that at this point in time there was no sign of recurrence of the malignancy.

To summarise, in the consultation reported in Data 1, patient nominates emotional problems early in anamnesis. The early nomination of depression and anxiety by patient is acknowledged and given space to be expressed by doctor, but then constructed *by doctor and patient together* as not requiring further discussion. Patient nominates a second psychosocial concern – fear – just before the physical examination (Data 3). But only after anamnesis and physical examination have been completed, does doctor explicitly invite patient to elaborate on her psychosocial concerns and is the problem accorded interactional space. As with the introduction of biomedical problems (see Chapter 4), the nomination of emotional problems in the Control group (both in this example and in the other consultations) is marked with discursive disfluency, hesitation and delay, as if the nomination of problems is not expected in this social situation – deviant from the norm ('dispreferred'; Schegloff, 2007; Clift, 2016; Mazeland, 2016). Companion formulates the basis of their fear in terms of the experiences of third parties, who were confronted with recurrence after periods of wellness. Doctor attempts to take away patient's and companion's worry, based on his medical expertise and experience: knowledge of the relevant statistics and the results of anamnesis and physical examination. One striking point in these data is the persistence with which patient and companion (re-)introduce their fear of recurrence. It seems that their need of reassurance was not met until doctor's final assessment and promise of further tests 'to make sure'.

The next section will focus on whether the discussion of emotional concerns changes with the introduction of the DT+PL, and if so, how.

2.3 The qualitative analysis of a consultation from the DT+PL group

Patient in Data 6 finished treatment (CO2 laser surgery and radiotherapy) seven weeks before the consultation. She has filled out the DT+PL before the consultation and indicated on it that her overall distress level is 5, so she is considered to be suffering problematic distress (Tuinman et al., 2008). Patient crossed 13 elements on the PL, 12 of which are physical, and one emotional (concentration). At the start of the consultation, patient indicated very tentatively that she was doing reasonably well in the circumstances, but that she was still experiencing a lot of problems. Before the start of Data 6 (10 minutes into the consultation) doctor and patient discussed a number of patient's biomedical problems, physical after-effects of the treatment she has recently undergone. Data 6 starts when doctor and patient are moving into the discussion of the DT+PL. This is still part of the anamnesis.

Data 6

Dr A

P1	Dr:	.hh let's have a loo:k ((reads DT+PL)) (4.1) well a fi:ve on average distress (2.3) and that is mostly in the concentra:tion (1.1) in the obstipa:tion didn't you get any medication for the obstipa:tion↑	.hh eens even kij:ken ((leest DT+PL)) (4,1) nou gemiddeld een vij:f last (2,3) en dat zit dan met name in de concentra:tie (1,1) in de obstipa:tie had u geen medicijnen gekregen voor de obstipa:tie↑

Lines left out.
For about five minutes Dr and Pt discuss Pt's medication for obstipation, and then systematically move down the Problem List and discuss various biomedical complaints Pt has listed (mucus, dry congested nose, problems sleeping, taste, muscle strength and tiredness).
We enter the data again when Pt and Dr round off the discussion of tiredness.

P2	Pt:	and then you say like .hh and [knack]ered	en dan zeg je van .hh en [bek]af
P3	Dr:	[yes]	[ja]
P4	Pt:	yes	ja
P5	Dr:	yes	ja
P6	Pt:	yes: and as far as those concentration problems [are concerned]	ja: en wat die concentratiestoornissen [betreft]
P7	Dr:	[exactly]	[precies]
P8	Pt:	I just blame that on that mor↑phine,	dat wijt ik gewoon ook aan die mor↑fine,
P9	Dr:	yes (.) because that is the la:st thing really that I-that I see here of which I think gosh actually really	Ja (.) want dat is het laa:tste eigenlijk wat ik-wat ik zie staan waar ik van denk goh eigenlijk echt

		something that .hh eh	iets wat .hh eh
		for me is harder	voor mij moeilijker
		to pla:ce	te plaa:tse:n is
		I do understand of	ik begrijp natuurlijk
		course very well that if	heel goed dat als
		you are not feeling well	je op zich niet lekker in je vel
		that you are also	zit dat je dan ook
		a little worse in terms	qua concentra:tie iets minder
		of concentra:tion	lekker bent
		and certainly with	en zeker met
		[those]	[die]
P10	Pt:	[yes]	[ja]
P11	Dr:	medicines that you ha:ve	medicijnen die u hee:ft
P12	Pt:	yes	ja
P13	Dr:	hHh another r:eason	hHh een andere r:eden
		I can really not think	kan ik eigenlijk niet verzinnen
		of (.)	(.)
		how serious is it with	hoe ernstig is het met
		the concentra:tion	de concentra:tie
		do you leave the gas on	laat u het gas aan staan

Lines left out.
Pt and Cp elaborate on concentration problems and tiredness
for 40 seconds.

P14	Dr:	so you are a little	dus u bent af en toe
		absent-minded now and	afwezig een
		then	beetje
P15	Pt:	yes=	ja=
P16	Dr:	=yes yes I think perhaps	=ja ja ik denk misschien
		really also that that is	toch ook dat dat
		that tiredness a little	die vermoeidheid een beetje is
		eh	hè
		isn’t that possible↑	zou het niet↑
		.hh	.hh
		(0.2)	(0,2)
P17	Pt:	y[e:s] ((doubtfully))	j[a:] ((twijfelend))
P18	Dr:	[or]do you not know	[of]weet u het zelf
		yourself exactly	niet goed
P19	Pt:	no at a certain point	nee je komt op een gegeven moment
		you get to [such a]	in [zo'n]
		phase that you	fase dat je
P20	Dr:	[ye:s]	[ja:]
P21	Pt:	say like I’d really like	zegt van ik wil 't liefst gaan
		to sit down and s:ta:re	zitten s:ta:ren
		a while	even
		[on earth]	[op aarde]
P22	Dr:	[ye:s]	[ja:]
P23	Pt:	a moment a moment to be	even even
		earthed like	aarden van
P24	Dr:	yes:	ja:
P25	Pt:	=like oh yes well I am	=van oh ja nou ik ben er
		ba:ck again	wee:r
		uhmfff ((laughs))	uhmfff ((lacht))
P26	Dr:	but it is not that you	maar het is niet zo dat u
		↓eh ↓eh	↓eh ↓eh↓
		while you are watching	terwijl u televisie
		the telly suddenly start	kijkt ineens aan het
		worrying	piekeren bent
		or something	of zo
		that you [think] like	dat u [denkt] van

P27	Pt:	[no]	[nee]
P28	Dr:	no no	nee nee
P29	Pt:	no not really	nee hoor
P30	Dr:	it is not that you a:re sombre and that tha:t is why you cannot concentra:te	het is niet dat u somber be:nt en dat u zich daa:rdoor niet kunt concentre:ren
P31	Pt:	no: look	nee: kijk
P32	Dr:	neh	neh
P33	Pt:	>that< that sombreness that I do have of course but eh:m: now it is not so bad anymore really	>die< die somberheid die heb ik wel natuurlijk maar eh:m: nu valt het weer wel mee
P34	Dr:	ye:s=	ja:=
P35	Pt:	=↓but eh s-some eh two weeks ago I really had such a dip °that I felt like° pff	=↓maar eh z-zo'n eh twee weken geleden had ik echt zo'n dip °dat ik zoiets had van° pff
P36	Dr:	yes	ja
P37	Pt:	where is this go:ing but	waar moet dit hee:n maar
P38	Dr:	[yes]	[ja]
P39	Pt:	[that] is going OK now and fortunately ((nods at Cp)) we can [ta:lk] about it really well	[dat] gaat nu wel en gelukkig ((knikt naar CP)) kunnen we daar goed over pra:[ten]
P40	Dr:	[yes] ↓yes	[ja] ↓ja

In P1, Dr A picks up the DT+PL, looks at it, and says: '.hh let's have a loo:k' and starts reading the DT+PL. After 4.1 seconds she comments on what she is reading: 'well a fi:ve on average distress and that is mostly in the concentra:tion (1.1) in the obstipa:tion'. She then immediately focusses on the biomedical concern, asking after the medication patient received: 'didn't you get any medication for the obstipa:tion↑'. This early focus on biomedical issues matches findings in e.g., Cameron et al. (2015) and Ford et al. (1996), which show that doctors tend to prefer discussing physical issues rather than emotional distress. Also, it matches doctor A's avowed procedure for discussing the DT+PL: during the training session she stated that she would first go through her ordinary procedure, and get the physical concerns out of the way, before looking at the DT+PL.

For about five minutes (not in transcript in Data 6) doctor and patient together discuss various biomedical problems patient has crossed on the PL. During this discussion patient indicates that the after-effects of the treatment she has had are lasting much longer than she had expected. In P2-P5 doctor and patient are finishing the discussion of the last of the physical after-effects on the PL, patient's tiredness.

In P6 patient returns to the only emotional problem she has crossed on the list and which doctor nominated in P1: ‘and as far as those concentration problems are concerned’. Deictic ‘those’ shows that patient links back to doctor’s reference to the concentration problems. Doctor responds with a partly overlapping ‘exactly’, signifying strong agreement and ratifying patient’s re-initiation of the topic. Together doctor and patient have now discursively constructed relevance for the discussion of patient’s emotional concern at this point in time. However, patient immediately continues by offering a lay, biomedical, diagnosis for the problem: ‘I just blame that on that mor↑phine’, with deictic ‘that’ linking back to their earlier discussion of the dosage of the morphine she is still taking (not in transcript). Apparently patient is aware that drowsiness – which links to concentration problems – is a common side effect of morphine; knowledge she may have garnered from the drug information leaflets patients receive when the drug is prescribed, and which has changed her epistemic status relative to this biomedical information from ‘unknowing’ to ‘knowing’ (Heritage, 2013).

Doctor seems to accept patient’s suggestion with ‘yes’, but this turns out to be a pro-forma agreement (Schegloff, 2007), because, after a micropause, she immediately problematises patient’s lay diagnosis of the cause of her concentration problems, saying she finds them ‘harder to pla:ce’. Disagreement is interactionally dispreferred (Pomerantz, 1984) and constitutes a face threat (Brown & Levinson, 1987/1978). Here, this is marked/mitigated with delay in the form of a preamble, disfluency, fillers and hesitation: ‘because that is the la:st thing really that I-that I see here of which I think gosh actually really something that .hh eh for me is harder to pla:ce it’ (P9). Doctor then provisionally postulates a number of possible causes which are linked to what patient has divulged about her condition, ‘I do understand of course very well that if you are not feeling well that you are also a little worse in terms of concentra:tion and certainly with those medicines that you ha:ve’. Her conclusion (‘hHh another r:eason I can really not think of’) seems a confirmation of patient’s lay diagnosis.

Doctor then leaves off suggesting possible causes for the time being and starts to probe the severity of the issue (not in transcript). Having established that the concentration problems are not dangerous, doctor picks up where she left off and continues to explore possible explanations. In P16, doctor suggests that the tiredness they discussed earlier in the consultation might be a cause: ‘I <u>think</u> perhaps really also that that is that tiredness a little eh isn’t that possible↑ .hh’. The suggestion – which contradicts patient’s lay diagnosis – is formulated tentatively, as a mere thought ('I think') with an uncertainty marker ('perhaps'), and minimisation ('a little'). With 'also', doctor indicates that this might be a cause *in addition to* patient's diagnosis. The suggestion is followed by a yes/no question explicitly inviting confirmation of this suggestion ('isn't that possible↑'; a yes-valenced question; Heritage, 2010). Patient, after a short pause, seems to tentatively provide the requested confirmation with a doubtful 'ye:s' (P17), orienting to the type-conformity preference of answering a yes/no question with a yes or a no (Raymond, 2003), and to the preference for agreement (Pomerantz, 1984), while at the same time her tone of voice indicates she is not really convinced (prosody trumps content, cf. Sacks, 1975). Doctor then – perhaps in response to the tentativeness of patient's 'yes' – offers patient an opportunity to refute the possibility of tiredness as a cause, with the suggestion of an alternative option (indicated by 'or'), again formulated as a yes/no question, 'or do you not know yourself exactly'. By giving patient the option to agree with the second suggestion, patient can implicitly disagree with the first one, without committing the face-threatening act (FTA) of openly (bold-on-record) disagreeing with doctor (Brown & Levinson, 1987/1978).

Patient now takes the opportunity doctor provides to 'neutrally' resist doctor's first suggestion; she responds with 'no', and so establishes that she is not sure what might be the cause. She then elaborates her answer by accounting for the negation (cf. Stivers & Heritage 2001), launching into a description of what she experiences (P19-P25): at times she hits a phase when she would 'really like to sit down and s:ta:re a while' (P21), with a descriptive lengthening of the word stare. She feels the need to become spiritually grounded, 'a moment a moment to be earthed like' (P23), to realise – with some hesitation and hedging – 'well I am ba:ck again uhmfff ((laughs))' (P25). With this, she gives an evocative description of a person trying to come to terms with the difficult experience of recovering from cancer. The problem she is coping with is not just the tiredness, but recovering from the shock of having had a brush with cancer; her response implies that as a cancer survivor "it is difficult to face an uncertain and potentially dreaded future with seemingly little control" (Beach et al., 2005, p. 905).

Doctor picks up on this elaboration with two questions which open up the possibility that worry (P26) or depression (P30) – psychosocial issues which frequently occur in cancer survivors (see Gil et al., 2012, Ghazali et al., 2013) – might be the cause of the concentration problems. Doctor's topicalisation of these 'new' emotional problems, which patient had not indicated on the PL, is formulated in a way that is strongly mitigated, very tentative, and sensitive to the face threat of postulating psychosocial issues that have not been pre-nominated by patient herself (cf. Biddle et al., 2016; Cameron et al., 2015). The first question includes delay (↓eh ↓eh) and hedging ('or something'), and both questions are negatively valenced, 'it isn't that', with a denial as the type-preferred response; they are as such optimised questions that make it easy for patient to refute this possibility and give a positive health response (cf. Heritage 2010). Patient duly denies that 'worry' and/or 'sombreness' are the cause of the concentration problems with a stretched, emphatic 'no:', and announces (P31) that she is going to explain: 'look'. This discourse marker opens up the possibility of an extended multi-unit turn (Schegloff, 1982). Patient links her explanation to doctor's preceding question by means of a deictic element (>that< that) and an 'embedded' repetition (sombreness/sombre) (Jefferson, 1978). Patient has now established that she will enter into an extended turn which is relevant to what has been discussed before, and doctor, accordingly, throughout patient's monologue responds with minimal responses, indicating she is actively listening and encouraging patient to continue talking.

Patient concedes that she does have sombreness (P33) – , '>that< that sombreness that I do have of course' – but with 'of course' she naturalises her sombreness as a normal side-effect of having cancer, as an 'inevitable consequence of [the] disease and its treatment' (Arora, 2003, p. 793), and therefore as something that is taken for granted and, probably, not even worth mentioning, or worth indicating in the PL (cf. Arora, 2003; Maguire, 2002). She also minimises the sombreness as something that has grown less, 'now it is not so bad anymore really', and indicates she had a dip two weeks ago, but that is over (P35; trouble resistance; Jefferson, 1988). She concludes with the remark that she and companion – whom she includes in her account with a nod – can 'fortunately […] talk about it really well' (P39). This implies that, all things considered, in her opinion her sombreness is not doctorable, and so not topicalisable in the current context of a follow-up consultation (Heritage & Robinson, 2006a; cf. Van der Linden et al., 2016): no help from the medical profession is required. Patient's response matches findings of earlier studies that show that patients suffering high emotional distress often decline help (e.g., Buchold et al., 2015; Clover et al., 2015; Zenger et al., 2010; Zwaan et al., 2012), with Clover et al. (2015) showing that the majority give as the reason for declining help that they are able to cope themselves.

Patient's ability to cope is confirmed in the post-consultation interview with patient and companion. When asked what she thinks of the inclusion of questions on emotional issues in the DT+PL and in the consultation, patient indicates that this might be relevant for other patients, who do not have a network of people whom they can turn to. For herself, it is not necessary, because she can talk about things with her friends and family.

Data 7
Interview patient Dr A

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Patient:    Look, now I fortunately still have people around me, X
            (first name partner), and I have my daughter and I have eh
            three sisters. They live a bit further away, but that is
            every day ehm, right, you know via  email eh we communicate
            for a bit. And that is a great help. But I think if you
            don’t have so many relations or friends or acquaintances,
            yes then it will have an enormous emotional impact on you.
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To summarise, Data 6 shows that the DT+PL has changed doctor’s epistemic status relative to patient’s emotional distress to ‘knowing’, which has triggered her to nominate an emotional issue, i.e. patient’s concentration problems. Doctor and patient co-construct patient’s concentration problems as topicalisable, and consequently as needing interactional room to be explored. During the episode that follows, *patient* offers a biomedical explanation for the issue (based probably on what she has gathered from the information leaflet accompanying her prescription), while *doctor* initiates an exploration of other possible psychosocial causes, nominating a number of emotional possibilities, including worry and sombreness. These suggestions are refuted by patient; they are – according to her – not relevant topics to discuss with this doctor at this point in time (cf. Biddle et al., 2016).

3.0 Discussion and conclusions

In the Control group only a very small number of the emotional problems patients indicate in the DT+PL are addressed in the consultations. This small number matches the findings in previous studies (see Arora, 2003; Beach et al., 2005; Detmar et al., 2000; Detmar et al., 2002; Ford et al., 1996; Maguire, 1999). In the DT+PL group, a much larger percentage of patients’ emotional concerns was discussed. This shows that the DT+PL seems to fulfil its function as a tool to stimulate the discussion of psychosocial issues (see also Chapter 6).

This chapter has complemented information relating to what problems are nominated by whom and at what point in the consultation with a fine-grained analysis of *longer sequences* to present a picture of the interactional work that is done by both doctor and patient to co-construct the discussion of emotional distress (see also Cameron et al., 2015) in the two conditions. It presented a detailed analysis of two sets of data, one from the Control group (Data 1-5) and one from the DT+PL group (Data 6-7). This analysis leads to the following conclusions:

1. The information on the DT+PL impacts the epistemic status of the physician relative to patients' – hitherto undiscussed – emotional problems from 'unknowing' to 'knowing' that they exist (Heritage, 2013). This has an effect on the *nomination* of emotional issues as a topic for discussion during the consultation. As the quantitative information in Table 1 shows, in the Control group emotional problems were only nominated by the patients and their companions. In the DT+PL group doctors also nominated emotional issues, in response to patients' *prenomination* of these problems in the DT+PL. By changing the epistemic status of the doctor, the DT+PL creates the affordances for the doctors to proactively (Data 6) instead of reactively (Data 3) create relevance for the discussion of emotional distress in cancer follow-up.
2. Whether topic nomination also led to discussion was a matter of negotiation between the participants: in both groups doctor and patient (and companion) *locally, discursively co-constructed* the interactional space the topic was eventually granted. This discursive construction could take multiple turns at talk, with delayed responses on both sides (Data 1, 3, 6).
3. Both the quantitative and the qualitative analysis seem to confirm the observation made by Zhou et al. (2015) that *at what point* in the consultation patient nominates emotional distress may influence whether it is indeed subsequently discussed (see Table 1). However, Zhou et al.'s findings of an optimal timing of six minutes into the consultation can be refined. The discussion of emotional distress may indeed have a *preferred timing*, but – rather than being a purely temporal matter – this may be related to the Act sequence of the speech event (cf. Hymes, 1977, Chapter 3): nomination occurred mostly late in anamnesis or after the physical examination. For instance, when patient in Data 1 at the very beginning of anamnesis nominates depression, it is given space to be mentioned, but it is not further addressed, with doctor and patient together constructing it as not relevant for discussion. However, when patient and companion nominate fear of recurrence after the physical examination in the same consultation, it is elaborately discussed (Data 3). These findings match

e.g., Frankel (1990) and Ten Have (1993), who have shown that there are preferred slots in the consultation for patients to ask questions: after anamnesis and physical examination have been completed. After the physical problems have been diagnosed, there is interactional space for questions but also for the discussion of psychosocial/emotional problems.

4. When emotional topics are raised by patients, the doctors in these data do not usually respond by entering into 'therapy talk' (Weiste & Peräkylä, 2015). Instead, they mostly try to 'fix' whatever problem patient raises. In this sense the follow-up cancer consultation resembles a service encounter (Ten Have, 1989). When discussing fear of recurrence, doctors do not focus on the emotional aspects of patients' fear, but use their epistemic role/medical expertise to take away those fears: for instance, after anamnesis and the physical examination they indicate that at this point in time there are no indications of recurrence; they explain that statistically – because 'enough' time has elapsed since treatment – there is less likelihood of recurrence; or they order extra tests (Data 3; see e.g., Beach & Dozier, 2015).
5. Patients, in their turn, may *resist* doctor's probing their emotional concerns (Data 6; see e.g., Buchold et al., 2015; Clover et al., 2015; Zenger et al., 2010; Zwaan et al., 2012). Patients do not always want help with their emotional issues, independent of what they indicate on the DT+PL. This was mentioned by the trainer in the DT+PL training which the doctors in this study underwent: '*We* tend to think that the patients want to be referred, but often they do not want it'. It matches the findings of Clover et al. (2015) that a large percentage of patients (71%) with significant distress (Distress Thermometer score 5 or higher) did not want help, with 46% of them saying they could manage themselves, and 23% claiming their distress was not severe enough (see also Buchold et al., 2015; Zenger et al., 2010; Zwaan et al., 2012).[53] The data from the DT+PL group further show that emotional distress is not always something patients see as relevant for discussion with *this* doctor, in *this* consultation (cf. Maguire, 1999; Sacks, 1975). A number of patients in this study indicated that they preferred to discuss such issues with their loved ones (as illustrated in Data 6 and 7) or with their GP; they see the oncologist as solely responsible for monitoring

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[53] See Tuinman et al. (2015) for an analysis of the relationship of desire for referral with age and marital status.

their biomedical status, as befits their epistemic role. One patient formulated this explicitly, when asked if they had any questions: ‘ Well nothing eh in your area’. So whether the oncologist should be charged with monitoring patients’ psychosocial distress in follow-up consultations is a moot point. Perhaps this should be left to other medical carers, such as the GP and oncological nurse.

6. Finally, when arguing for or against the relevance of the discussion of emotional and biomedical issues, doctor and patient each use argumentation that fits their knowledge and experience, doctors of course relying on their medical expertise and experience, and patients relying on knowledge they have garnered from a variety of sources, including patient leaflets, the Internet, their own physical experience, and the experiences of friends and family (Data 3, Data 6). When doctor and patient disagreed in the data, and so gave a ‘dispreferred response’, they formulated their replies with the utmost diffidence (indirectness strategies’), always making a strong interactional effort to mitigate loss of face (Data 3, Data 6).

Summary of results, discussion and conclusions, and limitations

1.0 Summary of results

In the Dutch medical context, patients who have been treated for cancer go through a surveillance programme often lasting four to five years, during which they are monitored for metastasis, recurrence of/new malignancies and the after-effects of the disease and its treatment, and doctors aim to relieve patients' anxiety (see e.g., National Cancer Institute, 2010). In the last two decades the realisation has grown that, routinely, too little attention is paid (for various reasons) to the psychosocial distress that cancer patients and cancer survivors experience (see e.g., Beach et al., 2005; Cameron et al., 2015; Detmar et al., 2000; Ford et al., 1996; Maguire, 1999; Taylor et al., 2011). The Distress Thermometer and Problem List (DT+PL; 'Lastmeter' in Dutch) has been recommended and widely introduced as a discussion tool to remedy this, and to stimulate the discussion of psychosocial issues in follow-up (NCCN, 1999; Integraal Kankercentrum Nederland, 2010; Tuinman et al., 2008; Van der Linden et al., 2016).

At the request of a team of Dutch head-and-neck oncologists on the brink of introducing the DT+PL in their consultations, the current research project has conducted a discourse-analytical study into the interactional effects of the introduction of this tool on doctor-patient communication in the follow-up head-and-neck cancer consultation.

To be able to make a comparison between the situation before and after the introduction of the DT+PL, first a benchmark study of the interactional context was conducted, making use of an ethnomethodological approach (Chapter 2). As in many other data-driven studies, a first analysis of the data brought up interesting questions that had not been envisaged when embarking on the project. So before entering into a comparison of the interaction in the two contexts, two separate studies were conducted focussing on data from the standard, scheduled follow-up head-and-neck cancer consultation (without the use of the DT+PL). The first study focusses on the 'How are you?' (HAY?) question used in the opening sequences of the consultation (Chapter 3); the second study focusses on the construction of the Key of the consultation (Chapter 4). The interaction in the two contexts is compared in Chapters 5, 6 and 7, where the focus is on what happens in the consultation when the DT+PL is introduced as a discussion tool: its effects on the contextual parameters of the follow-up consultation (Chapter 5), the discussion of psychosocial distress (Chapter 6), and the construction of the interaction between doctor and patient during the discussion of emotional distress (Chapter 7).

1.1 The benchmark: the consultation as a speech event

The standard follow-up head-and-neck cancer consultation is a well-defined institutional speech event (Ten Have, 1989). It is situated in an institutional, medical context with specific culturally established rules of behaviour that participants orient towards. Since participants' orientation towards these rules of behaviour influences the interaction, a thorough understanding of the context is important for the researcher.

The current study has described the contextual parameters of the follow-up head-and-neck cancer consultation in terms of Hymes's SPEAKING model (1977; Saville-Troike, 2003) as follows. The Situation of the consultation (a scheduled return visit with a 10-15 minute time frame, which takes place in an examination room in a cancer hospital); the Participants and their roles (crucially doctor and patient, with an optional companion, each with their respective roles); the Ends or aims of the consultation (to monitor patients for recurrence, new or second tumours and for after-effects of the disease and its treatment, and to reassure patients/relieve anxiety); the Act sequence (standard, default actions in the consultation, starting with an informal opening, anamnesis, the physical examination, discussion of findings, advice and next steps, and closing); the Key or mood of the consultation (an orientation towards wellness mixed with an orientation towards distress); the Instrumentalities (the channels through which communication takes place, including speech, writing and nonverbal/nonvocal communication); the Norms of interaction (e.g., who can say/ask what at which point in the consultation) and the Genre (medical interaction). These parameters influence each other and interact with each other, so that, e.g., the Ends of the event determine the roles of the Participants and the Act sequence; the place in the Act sequence determines the Norms of interaction, etc.

1.2 'How are you?': the transition from opening to anamnesis

When first analysing the interactions in the standard follow-up head-and-neck cancer consultations, a phenomenon that stood out was the similar way in which the opening of the consultation was constructed by the participants, more specifically, the consistency in the use of the question with which the physicians open their anamnesis and the way that patients respond. Similar to consultations described in earlier research (e.g., Coupland et al.; 1994, Frankel, 1995; Heritage & Robinson, 2006b; Rogers & Todd, 2010), the standard opening question which all the physicians in this study use is a variation on 'How are you?' (HAY?; Dutch 'Hoe gaat het met u?'). The HAY? question has a double function: it serves to set the 'topical agenda' of the consultation (the status of patients' condition), and the 'action agenda' for the next section of the consultation (for patients to assess and discuss their condition; Boyd & Heritage, 2006). Research in a wide range of Anglo-Saxon healthcare environments (mainly in the US and the UK; e.g., Coupland et al., 1994; Frankel, 1984; Rogers & Todd, 2010) has shown that patients may be confused about whether the question is meant socially (as still part of the greeting exchange before the start of the consultation proper) or medically (as the first question of anamnesis). However, the data in the current Dutch study show that the patients consistently interpreted HAY? as a medical inquiry, more specifically as a 'first concern elicitor' which asked them to report their medical condition (see e.g., Gafaranga & Britten, 2005; Heath, 1981).

Further analysis suggested the following possible reasons for the apparent consensus concerning the medical interpretation of the question in the data. First, the socio-cultural context might play a part. In the Anglo-Saxon medical context, doctor and patient meet each other in the consultation room, and the four tasks that create the medical context (greeting, establishing identity, checking records and embodying readiness; Robinson, 2013) all take place in that space, on the spot. This might lead patients to interpret the HAY? question as 'still part of the greeting sequence'. In the Dutch context of the current study, doctors routinely check patients' records beforehand, fetch their patients from the waiting room, and greet them there. The first three steps in creating the medical context have thus been established before both parties have entered the examination room and seated themselves at the doctor's desk. Then doctor asks the HAY? question, usually accompanied by a wide range of contextualisation cues that effectuate and facilitate the transition from social to medical context, such as discourse markers, gaze and reading patients' files (Coupland et al., 1994; Heath, 1981; Robinson, 2013). All this together facilitates a medical interpretation of HAY? questions (Heritage & Robinson, 2006b; Robinson, 2013).

Secondly, much of the earlier research does not differentiate between different medical contexts (e.g., Coupland et al., 1994; Frankel, 1995; Rogers & Todd, 2010). The context of the HAY? question is, however, important for its interpretation (see Gafaranga & Britten, 2005; Heath, 1981). The data in the current study are all of the same type: scheduled follow-up head-and-neck cancer consultations, i.e. they are all *return visits* in a predetermined series of consultations. Doctors are familiar with the complaints which patients voiced in earlier sessions, and patients are aware of this. Hence, the HAY? question is often formulated with explicit reference to this, by means of phrases like 'since your last visit', and patients interpret and answer the question accordingly as medically oriented, more specifically as soliciting an update of their medical condition (Heath, 1981).

The HAY? question does pose some problems for the patients, however. It is a complex question to answer for a person who has just had a bout with cancer. This is signalled by the delay and hesitation that is pervasive in the answers to this question in the data, and in the frequent juxtaposition of a positive first gloss next to a detailing of problems: patients are trying to combine in their answers that they are doing okay in the circumstances, and/or making progress in their recovery from cancer, but are frequently still suffering from invasive and debilitating after-effects (cf. Coupland et al., 1992 for an analysis of similar difficulties for geriatric patients).

1.3 The Key of the follow-up cancer consultation

Earlier research shows doctors and patients in cancer consultations frequently displaying elements of an orientation towards wellness, hope and optimism (see e.g., Beach, 2013; Beach, 2014; Gutzmer & Beach, 2015; Jarret & Payne, 2000; Leydon, 2008), resulting in a positive Key or mood. There are many reasons for an orientation towards wellness in the standard scheduled follow-up cancer consultation: wellness is what treatment is working towards; recurrences are usually found in *unscheduled* consultations whereas in scheduled consultations the chance of finding recurrence is relatively small (De Visscher & Manni, 1994; Korthari et al., 2011; Ritoe et al., 2004); society expects patients to move out of the sick role as soon as possible (Heritage & Maynard, 2006b; Parsons, 1951; Pilnick & Dingwall, 2011); and patients may attempt to relieve fear of recurrence by orienting towards wellness, thus 'talking wellness into being' as it were (Beach, 2013). Yet there are also many reasons to expect an orientation towards distress in follow-up, especially among head-and-neck cancer survivors. They often suffer from severe after-effects of the malignancy and its treatment, including continuous fatigue, disfigurement, problems with swallowing and eating, and problems with speaking resulting from the removal of the voice box and/or (part of) the tongue. This leads head-and-neck cancer survivors to experience stronger than average distress levels (Gil et al., 2012). All things considered, a *hybrid* Key was expected in the data, combining both an orientation to wellness and an orientation to distress.

A detailed analysis of the interactional data confirms earlier research and shows that doctors and patients do indeed orient towards wellness in a number of ways. Doctors frame wellness as 'feeling better than before' or 'doing well in the circumstances' in the opening HAY? question of the consultation, which makes it possible for patients to offer a positive health outcome (Heritage, 2010) and thus a wellness-oriented response. In anamnesis, the doctors frequently use questions designed to elicit 'no problem' responses from the patients (see e.g., Beach, 2013; Boyd & Heritage, 2006), especially to confirm that patients have no complaints in the area affected by malignancies and are eating and drinking well. And during the physical examination they give a running (positive) commentary of what they see (Beach, 2014; Jones, 1997). Responding to patient worries and questions, doctors provide reassurance by means of generic biomedical responses (Beach & Dozier, 2015) which indicate that the symptoms patients experience are 'normal' or that they usually diminish. Patients orient towards wellness by giving 'no problem' answers to doctors' questions; by confirming doctors' 'no problem' statements and by volunteering positive news (see e.g., Beach, 2013; Boyd & Heritage, 2006); by minimising or denying their symptoms (see e.g., Beach 2013; Jarret & Payne, 2000, Roger & Todd, 2010); and by claiming to be working towards a healthy lifestyle (Beach, 2013). However, as expected, problem orientation also frequently occurred in the data. To create doctorability for the after-effects of treatment, patients emphasise their distress through intonation and hyperbole. Doctors respond to this by asking problem-oriented follow-up questions, which in their turn receive problem-oriented answers. Also, when relevant, doctors, of course, report their problematic observations during anamnesis and the physical examination.

Strikingly, the way in which both doctors and patients nominated problems, i.e. *first* raised them as a topic for discussion, was (apart from one exception) always heavily mitigated, marked by delay, hesitation and disfluency. Such discursive cues would indicate that the introduction of problems might be dispreferred in the conversation analytical sense (Schegloff, 2007; 'complex' Mazeland, 2016; 'reluctant' Clift, 2016). By constructing the introduction of problems as dispreferred, participants place them outside of what is 'expected' or 'normal' in the context of the follow-up head-and-neck cancer consultation, which would lend strength to the notion that in spite of the fact that orientations to both wellness and distress occur side by side in the data, such consultations are *in essence* geared towards an orientation to wellness.

1.4 Comparison of two contexts: consultation with and without the DT+PL

Chapters 4, 5 and 6 discuss whether, and if so how, the introduction of the DT+PL affects the interaction in general and more specifically the discussion of psychosocial issues in the follow-up head-and-neck cancer consultation.

Apart from problems noted on the DT+PL, many other issues are discussed in the consultations. This shows that, in spite of the attempts of HRQL instruments at being all-inclusive, there will always be problems that are important to the patient and that do not appear on the list (Higginson & Carr, 2001). Also, for a number of reasons, patients are not always complete in what they list on the PL; they may simply forget to write problems down or may not consider them relevant. The DT+PL can therefore not be considered a complete record of patient's problems, and the discussion of patient's condition should not be limited to the discussion of the DT+PL. The doctors show that they are aware of this pitfall by doing their 'normal' anamnesis first and/or by asking follow-up questions targeted at uncovering any further problems.

Doctor and patient co-construct, locally, discursively, and often over multiple turns, the interactional space for further discussion of psychosocial problems. When doctors nominate emotional concerns, patients are not always willing to discuss them or accept help (cf. Buchold et al., 2015; Clover et al., 2015; Zenger et al., 2010; Zwaan et al., 2012). Patients do not always see this topic as relevant for discussion with their oncologist (cf. Biddle et al., 2016; Maguire, 1999; Sacks, 1975), preferring to discuss such issues with others, such as their GP or their loved ones. When doctors and patients argue about the relevance of a topic for discussion, whether it is psychosocial or biomedical, they use a wide range of 'indirectness strategies' to mitigate possible loss of face (Brown & Levinson, 1987/1978) through the dispreferred action of disagreeing (Pomerantz, 1984).

Looking at the frequency with which emotional issues are discussed under the two conditions (without and with the DT+PL) a small positive quantitative effect of the introduction of the DT+PL can be reported.[54]

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[54] Since the dataset is small, there was no way to calculate the statistical significance of this finding.

- By both doctors, a higher percentage of patients' emotional concerns is topicalised and discussed, and so the gap between the number of problems patients experienced and the number of problems that were discussed was diminished. This can be considered a positive effect of the tool. It matches earlier findings related to the introduction of PROMs (patient-related outcome measures) like the DT+PL on the discussion of psychosocial issues (e.g., Detmar et al., 2002; Velikova et al., 2004).

  Although it cannot be ruled out that this may be partly due to participants' awareness of being observed (Observer's paradox; Labov, 2006; Hawthorne effect; Sedgwick & Greenwood, 2015), other possible reasons that suggest themselves might be that filling out the DT+PL prior to the consultation has 'primed' patients to discuss their psychosocial issues, and that doctors have been made aware of these issues by seeing them 'pre-nominated', and have been triggered to discuss them by the fact that patients have, as it were, put them on the agenda of the consultation.
- There is a difference between the two doctors in how many problems are discussed. This may be due to two factors: the problem load of the patients (if a patient has a high problem load, there is simply more to discuss), and the different discursive approaches the doctors have towards the discussion of the DT+PL. A point-by-point discussion leads to a smaller gap between points noted on the PL and points addressed than a holistic approach.

Although a higher percentage of patients' (emotional) problems is discussed in the DT+PL consultations, still many of the problems indicated on the DT+PL remain undiscussed in the consultations. There are several possible reasons for this.

- It may result from a contextual parameter: *time*. The consultations are scheduled for a 10-15-minute timeslot. In cases of high problem load, it may not be possible to discuss all the problems without overshooting the time limit of the consultation.
- Another factor is the topic selection by both doctor and patient. As a discursive strategy to focus the discussion and use time efficiently, doctors may choose to open the discussion of the DT+PL by asking the patient to nominate which problems are new or most pressing. Patients, on the other hand, may not want to discuss certain issues because they do not consider this doctor and this occasion the right

context for discussing them (Biddle et al., 2016; Maguire, 1999; Sacks, 1975).

- The design of the DT+PL may also play a role: it does not distinguish between cancer-related and other problems (see also Higginson & Carr, 2001), which may lead participants to select only those topics for discussion which are most relevant to this occasion.

A close analysis of the data, including longer stretches of talk, shows that the introduction of the DT+PL as a new Instrumentality (Hymes, 1977) affects other contextual parameters.

- It has an impact on the role of the patient: it increases patients' agency, enabling them to pre-nominate (psychosocial) problems as possible topics for discussion on the DT+PL.
- The DT+PL changes the epistemic status of the doctor from 'unknowing' to 'knowing' (Heritage, 2013) with respect to the psychosocial/emotional problems that patients encounter. The change to 'knowing' that problems exist creates affordances for nominating them: it stimulates doctors to initiate the discussion of those issues, which they do not routinely do in consultations without the DT+PL.
- In the discussion of emotional distress, both with and without the use of the DT+PL, doctors tend to stick to their perceived role of medical professional, i.e. they focus on biomedical ways of relieving distress; they do not routinely enter into 'therapy talk' directed at curing problems by talking about them (Weiste & Peräkylä, 2015). For instance, when responding to fear of recurrence they give responses grounded in their epistemic role/medical expertise to take away patients' anxiety, ordering extra tests 'just to make sure';[55] indicating that in this patient's case the time of most risk is over; and that their physical examination shows no signs of recurrence (Beach & Dozier, 2015).
- The data suggest that there may be a preferred timing for the introduction of emotional problems (cf. Zhou et al., 2015) later on in the Act sequence (Hymes, 1977) of the consultation. After anamnesis and the physical examination have been completed, and doctors have the information they need for diagnosis, there is interactional space for psychosocial/emotional issues to be discussed (cf. Frankel, 1990; Ten Have, 1993).

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[55] However, ordering extra texts may also create more unrest.

The use of the DT+PL also introduces a number of dilemmas and complications for the participants in the follow-up head-and-neck cancer consultation: the problems of how to fit the discussion of the DT+PL into the standard Act sequence of the consultation, and how to manage time with the introduction of an extra element into the consultation. The two doctors in the DT+PL study each employ different strategies to solve these dilemmas.

2.0 Discussion and conclusions

This thesis has shown that in order to understand what happens in institutional speech events such as the head-and-neck cancer follow-up consultation and to account for the ways in which its participants co-construct the interaction, we have to adopt a context-sensitive approach.
We need to both:

- Take a wide perspective and analyse how the interaction fits in and is influenced by the cultural and institutional contextual parameters of the speech event, and
- Take a narrow perspective and focus on how the interactants discursively co-construct the speech event as it develops.

The multi-method design of the study, including insights from ethnography of communication and discourse analysis (more specifically conversation analysis and pragmatics), combines interviews with doctors and patients reflecting on the follow-up head-and-neck cancer consultation with a qualitative analysis of video-recorded consultations and descriptive quantitative data on discursive patterns that surfaced in the interactions. This broad design made it possible to trace not just what issues are discussed in the consultation and how frequently they are discussed, but also how the participants co-construct the interaction, what contextual parameters influence this, how the DT+PL affects all this, and how doctors and patients view the follow-up consultation and the DT+PL.

The use of an ethnographic approach to context – using observation of the speech event in operation combined with interviews with the participants, and analysing these data by means of Hymes's (1977) SPEAKING model – has laid bare the various contextual parameters that influence doctor-patient interaction in the follow-up head-and-neck cancer consultation. This approach made it possible to discover:

- How the cultural institutional parameters of the Dutch medical context are different from the Anglo-Saxon (US and UK) medical contexts, and

how this difference affects the interpretation of the ‘How are you?’ question at the start of anamnesis.
- How the Key of the consultation is affected by the complex context of the consultation, i.e. both by the specific characteristics of patients from a particular patient group (head-and-neck cancer survivors, who statistically suffer from high levels of distress) and by the characteristics of a specific medical event (the follow-up consultation, which is oriented towards returning to wellness).
- And how the introduction of the DT+PL, a new Instrumentality in the interactional organisation of the consultation, affects the discursive roles of the Participants, and the agenda and topic selection – and so also the Key, Ends and Act sequence – of the consultations.

An important limitation of this study is that the dataset is small, and it is impossible, therefore, to generalise the data on statistical grounds. However, small-scale qualitative studies, focussing on the discursive construction of the consultation and the lived experience of the participants, make it possible to gain a deeper understanding of what happens in the communicative context of an institutional social situation as the result of the introduction of a new tool. Irrespective of whether or not such tools have the desired effect on the parameters they are meant to address, they will always influence how doctors and patients interact with each other. Therefore, the interactional effects of new tools should more widely be taken into account when decisions about their implementation are being contemplated.[56]

2.1 Is the DT+PL effective?

One positive effect of the DT+PL is that it stimulates doctors and patients to nominate emotional distress if it is noted on the Problem List. The data in the current study show that doctors who did not *of their own accord* nominate psychosocial/emotional distress before, did so after they saw such problems indicated on the Problem List. It would seem that the DT+PL here serves a double function: it makes doctors aware of the existence of psychosocial problems (cf. Detmar et al., 2002), and its physical presence in the consultation requires that the problems on it be discussed.

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[56] A case in point might be the introduction of the ‘elektronisch patiëntendossier’ (digital patient file), which includes large numbers of obligatory fields intended to register and monitor quality of care which must be filled out.

When considering whether or not the DT+PL should be widely implemented in follow-up head-and-neck cancer care, an important question to ask is: What problem is the DT+PL meant to solve? Integraal Kankercentrum Nederland (2010) states that in a recent report the Dutch Healthcare Inspectorate has stated that "hospitals need to pay structural attention to the psychosocial circumstances of the patient" (p. 2 *author's translation*). This implies that this has not been the case up to that point. This is an undesirable situation since emotional distress negatively affects health and healing (see e.g., House, 2015; Otto-Meyer, 2019; Powell et al., 2013; Shi et al., 2018). The DT+PL has been introduced to solve the perceived problem that emotional/psychosocial distress is not structurally discussed in follow-up. One measure of success for the DT+PL would then be whether it helps doctors and patients to 'structurally' pay attention to emotional/psychosocial distress in follow-up.

'Structural attention' is a broad term, which may be hard to define. If we define success in the first instance (and more practically) as 'more attention', the DT+PL can be considered a success: earlier research shows that the numbers of psychosocial issues being discussed when making use of PROMs like the DT+PL do indeed go up (e.g., Detmar et al., 2000; Van Nuenen et al., 2018; Velikova et al., 2004), and the numerical data in the small sample of the present project confirm this. Related to this, one of the aims formulated in Integraal Kankercentrum Nederland (2010) for the introduction of the DT+PL is the following: "The DT+PL serves first and foremost as a base for an open dialogue in which the physician and/or nurse by means of a conversation explore the seriousness and type of a patient's problems and needs so as to arrive at the necessary basic psychosocial care or referral" (p. 24, *author's translation*). With a more frequent discussion of psychosocial issues "the door to a dialogue with clinicians" (Mitchell, 2013, p. 219) seems at least to have been opened a little more widely, and this aim seems to be met at least partially.

However, although a higher percentage of patients' emotional problems is discussed when the DT+PL is used, still not all patients' problems are explored in the consultation. This might be a possible explanation for the inconclusive results of earlier quantitative research into the effectiveness of the DT+PL, with some studies reporting limited improvement in quality of life (Velikova et al., 2004) and others reporting no significant improvements (Boyes et al., 2006; Hollingworth et al., 2013) or mixed results (Kotronoulas et al., 2014).[57] This

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[57] This might also partially explain the finding that the introduction of the DT+PL has, in the current data, not led to a higher patient-satisfaction score.

lack of effect may be related to the – still – incomplete discussion of patients' issues. This incompleteness might be due to the following barriers to the discussion of psychosocial distress, which might prevent patients from receiving the care they need.

2.2. Barriers to the discussion of psychosocial distress

With or without the DT+PL, there are barriers underlying the routine lack of discussion of psychosocial distress which need to be taken into account. Some of them are dependent on the Setting, and some on the Participants, their roles and their preferences:

1. It should be noted that the list of possible problems on the DT+PL is wider than the definition of distress used by IKNL and NCCN. Their definition limits problems relevant to distress as being of a "psychological (cognitive, behavioural, emotional), social and/or spiritual nature" (NCCN, 2015), while the DT+PL also includes physical problems and 'practical problems', such as transport, housekeeping and insurance.[58] Patients can indicate 47 different problems on the DT. This wide range of possible problems seems to be symptomatic for instruments that measure quality of life and leads to possible difficulties when implementing such instruments. Clover et al. (2016) note that this "significantly increases the time required for screening and lowers utility in clinical settings" (p. 4450). This is especially problematic with patients who have a high problem load.

   In any case, including the discussion of 'extra' issues in the consultation is problematic. In the interviews, doctors indicated that the time scheduled for follow-up consultations (10-15 minutes) does not allow for the further encroaching of extra tasks. Simply sticking to the standard way of conducting the consultations – which means not proactively asking after or broaching the topic of emotional distress – takes up all that time already (cf. Mitchell, 2013).

   However, time problems may be partially solved by means of specific discursive strategies such as prioritising elements of the DT+PL that patients indicate as being new or only discussing the most troublesome and leaving the rest.

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[58] In their training programme preparing them for the use of the DT+PL, the physicians in the current study expressed concern about this last category, indicating they felt that the relevance of these issues to their consultations and to their specific abilities to provide help were very limited.

2. In the interviews in this study, doctors indicated that they feel less than completely comfortable discussing psychosocial issues (cf. Mitchell, 2013). They are trained oncological surgeons and radiation oncologists; *ergo*, they have not been explicitly trained (and as a result feel they lack the expertise) to determine whether the distress patients experience is 'normal' distress – i.e. of a level that is to be expected for someone who has experienced a malignancy, a natural response – or distress that is more than normally severe so that patient needs to be referred to a specialist. The standard skill set of the oncologist may simply not include the informed discussion of emotional/ psychosocial issues.
3. The oncologists in the current study and elsewhere (e.g., Mellblom et al., 2016) tend to respond to the disclosure of distress in a task-focussed manner. Rather than routinely engaging in therapy talk geared to solving problems by talking (Weiste & Peräkylä, 2015), the physicians in this study display a communication style that is geared to fixing problems, as in a service encounter (Ten Have, 1989). If patients experience distress, e.g., fear of recurrence or unexplained fatigue, doctors routinely attempt to 'fix' this problem (i.e. relieve patients' anxiety) in a practical, biomedical fashion through extra tests, reporting positive results of the physical examination, or explanations of relevant statistics.
4. The data show that screening for distress by means of the DT+PL does not necessarily equal screening for desire for support (see also e.g., Clover et al., 2015; Salander, 2017). Patients with (severe) problems often do not wish to be referred to specialist help; they indicate they can cope (see also Buchold et al., 2015; Zenger et al., 2010; Zwaan et al., 2012). Neither do they always wish to discuss their problems with this particular doctor at this particular time (Buchold et al., 2015; Clover et al., 2015; Maguire, 1999; Sacks, 1975; Zenger et al., 2010; Zwaan et al., 2012). Patients decide for themselves who they want to discuss their problems with and who they want help from, which may be their GP, psychologist, coach, social worker, loved ones (partner, family, friends), or their oncologist.
5. Patients' own preconceptions of what is relevant for discussion in *this* consultation may result in them choosing not to note down specific problems on the PL or declining to discuss them in the consultation. Patients may consider some (emotional) problems, such as the fear of recurrence or feeling down, to be so 'normal' and 'natural' and 'obvious' in the circumstances that they do not rate them as doctorable

or mentionable (see also Salander, 2017; Mitchell, 2013). Also, since there is a pervasive orientation to wellness in the follow-up head-and-neck cancer consultation, this may influence whether issues are felt to be urgent and therefore relevant enough to discuss. Apart from this, patients may simply forget to indicate certain problems, which – sometimes spontaneously and sometimes after prompting – they later bring up in the consultation. All in all, the DT+PL must not be considered a complete set of data on patients' problems (Biddle et al., 2016; Higginson & Carr, 2001). It cannot replace active monitoring and discussion in the consultation.

As a result of these barriers to the discussion of psychosocial/emotional distress, problems and issues that require treatment may remain under the radar, resulting in patients not getting the help they need. This may partly explain why research into the effectiveness of PROMs such as the DT+PL on patients' health outcomes shows mixed and unclear results.

2.3 Practical suggestions for the use of the DT+PL

In the course of this study, a number of practical suggestions have presented themselves.

1. Given the time constraints of the follow-up consultation and the oncologists' lack of specialist training in dealing with psychosocial issues, it is worth asking whether oncologists are the medical carers of choice for monitoring psychosocial distress. In many hospitals, it is not the oncological surgeons or radiation oncologists who discuss the DT+PL with the patients. This task is often delegated to specialised oncological nurses (for The Netherlands, see e.g., Van Nuenen et al., 2017).[59] In the hospital at which the current study was conducted, monitoring by the oncological nurse stops at the end – or sometimes a few weeks after the end – of treatment. The hospital might consider whether an extension of this service into the follow-up trajectory is advisable, with the use of the DT+PL as an instrument to monitor distress.[60]

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[59] The DT+PL is routinely administered by paramedics, especially during rehabilitation in the first few months after treatment. It is not routinely used in follow-up. Other PROMs/PREMs are regularly administered in follow-up, but the standard implementation of their use during the consultation has so far not gone smoothly.

[60] Some studies show that changes in HRQL might be a first sign of recurrence. This might be an additional reason to monitor and compare levels of distress by means of a version of the DT+PL or other PROMs/PREMs, and incorporate them in patients' electronic medical file.

2. If the DT+PL is implemented, it might be useful to organise training sessions for the relevant caregivers not just in the use of the DT+PL but also in the discussion of psychosocial/emotional distress. Also, if the DT+PL is implemented the hospital might want to organise regular peer coaching sessions conducted by the people who use it so that they can share what works and what does not.
3. When using the DT+PL, it might be useful for caregivers to formulate the goal of the DT+PL in the first moments of the consultation and indicate that it will be discussed at some point in the consultation. This sets the agenda and lets patients know how the form they have just filled out will be used in the consultation.
4. The HAY? question that doctors routinely use to open anamnesis elicits information that may overlap with what the patient has indicated on the DT+PL which doctor has just received. Doctors may wish to adapt the formulation of the question to accommodate this overlap or they may topicalise the interactional dilemma they are faced with.
5. It is useful to realise that patients may not wish to discuss emotional problems with a particular caregiver or may not consider emotional issues a relevant topic for discussion at all. Many patients consider emotional distress after having undergone a bout of cancer as so normal that it is not worth mentioning it to a doctor. Asking patients whether they can cope or need extra help might be a good way to open up the discussion.
6. For maximum time-efficiency, consider focussing the discussion of the DT+PL on patients' most pressing or new problems (see also Clover, 2016). If completeness is the aim, a point-by-point discussion is the best option.
7. However, it is important to also ask an open question such as "Is there anything else you would like to discuss?" or "What other points would you like to discuss?" to make sure that patient has the opportunity to fill the gaps in the DT+PL.

3.0 Future research

From the current study it is not clear whether the DT+PL is the best instrument to stimulate doctors to discuss patients' psychosocial/emotional distress. One of the problems with the design of the instrument is that, with its 47 possible causes of distress, it may function more as a scattergun, targeting a wide range of possible causes for distress (see Higginson & Carr, 2001), without focussing on what the patient at this stage thinks is important to discuss with this doctor.

There seem to be a number of more practical ways to stimulate the discussion of psychosocial distress in follow-up, which might be tested in a new study.

- As suggested by Doctor A in the training session on using the DT+PL, one might simply add in the protocol that doctors should ask at regular intervals whether the patient is coping in their new situation, and if not, what help they need (compare Salander, 2017). This is also what is advocated by Palmer et al. (2011), who argues that the benefits of screening cancer patients for distress have not been shown, and that “offering patients the chance to discuss their concerns, regardless of screening, may make a more substantial contribution to their well-being” (p. e277).
- In Denmark a trial was conducted focussing on the use of an App with a very simple questionnaire that patients fill out before they see the doctor for follow-up (*BoB Borger og Behandler: skaber ro i hverdagen*~ “Patient and treatment: create calm in everyday life”). It asks over the past week, among other things, “What worries me? What makes me happy? What do I want to achieve? What can I do myself? The answers give the professional a quick feeling of the ‘whole person’ – not only the biomedical concerns” (personal communication, Eva Ahrensburg, Denmark).

The current study has focussed on a limited dataset of very specific consultations with a very specific patient group to analyse the effect of the DT+PL on doctor-patient interaction. A follow-up project with a larger dataset and a more quantitative design might be indicated to further explore

1) whether or not the longer duration of a number of the DT+PL consultations is due to the DT+PL, the discursive strategies of the physicians, the problem load of the patients or other, not yet identified possible reasons,
2) what the effects of the DT+PL are on who initiates what topic at what point in the consultation, and
3) whether different types of problems are associated with the same discursive devices e.g., whether after-effects are mitigated in the same way as possible signs of recurrence, and whether short-term after-effects are discussed with the same intensity as long-term after-effects.

A separate question that merits further investigation is whether or not the pervasive orientation towards wellness in the follow-up head-and-neck cancer consultation inhibits patients from mentioning problems.

Caveat

The present study has looked at the standard, default organisation of the consultation and how it is affected by the DT+PL. It has looked at what happens when the DT+PL is introduced; it has shown different ways of using the DT+PL in consultations; it has identified some obstacles in the discussion of psychosocial distress and made some practical suggestions. However, the practical suggestions that have been formulated on the basis of the analyses must be seen as guidelines only – the interactions are collaboratively constructed by doctor and patient, and what works with one doctor and one patient in one consultation may not work with another pair, or in other circumstances. Whether problems are discussed adequately or whether the DT+PL is the best instrument to stimulate this, is difficult to ascertain and outside the scope of this thesis.

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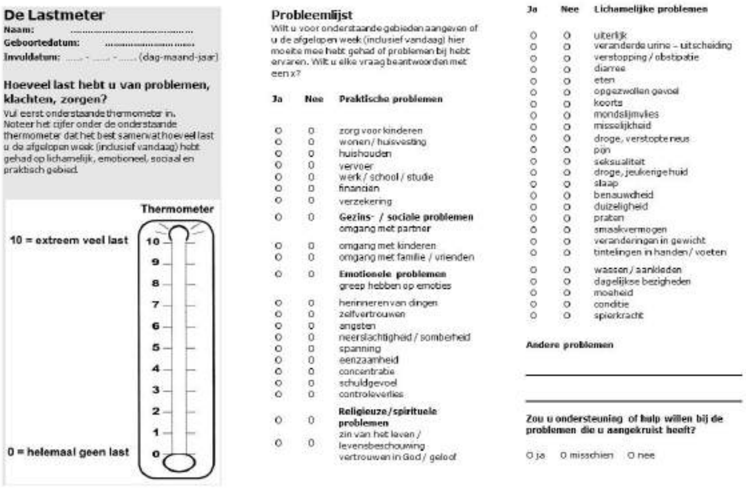
Appendix 1

Dutch version of the DT+PL



De Lastmeter

Naam: ………………………………

Geboortedatum: ……………………

Invuldatum: …… - …… - …… (dag-maand-jaar)

Hoeveel last hebt u van problemen, klachten, zorgen?

Vul eerst onderstaande thermometer in. Noteer het cijfer onder de onderstaande thermometer dat het best samenvat hoeveel last u de afgelopen week (inclusief vandaag) hebt gehad op lichamelijk, emotioneel, sociaal en praktisch gebied.

Probleemlijst

Wilt u voor onderstaande gebieden aangeven of u de afgelopen week (inclusief vandaag) hier moeite mee hebt gehad of problemen bij hebt ervaren. Wilt u elke vraag beantwoorden met een x?

Ja	Nee	Praktische problemen
○	○	zorg voor kinderen
○	○	wonen / huisvesting
○	○	huishouden
○	○	vervoer
○	○	werk / school / studie
○	○	financiën
○	○	verzekering
		Gezins- / sociale problemen
○	○	omgang met partner
○	○	omgang met kinderen
○	○	omgang met familie / vrienden
		Emotionele problemen
○	○	greep hebben op emoties
○	○	herinneren van dingen
○	○	zelfvertrouwen
○	○	angsten
○	○	neerslachtigheid / somberheid
○	○	spanning
○	○	eenzaamheid
○	○	concentratie
○	○	schuldgevoel
○	○	controleverlies
		Religieuze / spirituele problemen
○	○	zin van het leven / levensbeschouwing
○	○	vertrouwen in God / geloof

Ja	Nee	Lichamelijke problemen
○	○	uiterlijk
○	○	veranderde urine – uitscheiding
○	○	verstopping / obstipatie
○	○	diarree
○	○	eten
○	○	opgezwollen gevoel
○	○	koorts
○	○	mondslijmvlies
○	○	misselijkheid
○	○	droge, verstopte neus
○	○	pijn
○	○	seksualiteit
○	○	droge, jeukerige huid
○	○	slaap
○	○	benauwdheid
○	○	duizeligheid
○	○	praten
○	○	smaakvermogen
○	○	veranderingen in gewicht
○	○	tintelingen in handen / voeten
○	○	wassen / aankleden
○	○	dagelijkse bezigheden
○	○	moeheid
○	○	conditie
○	○	spierkracht

Andere problemen

____

____

Zou u ondersteuning of hulp willen bij de problemen die u aangekruist heeft?

○ ja ○ misschien ○ nee

Appendix 2

Transcription conventions

P : Position of the utterance in the sequence

Dr : Doctor

Pt : Patient

Cp : Companion

((   )) : contextual information; meta-comments

[: overlapping utterances

= : immediately adjacent utterances

(.) : pause

(2.1) : timed pause

< > : slower than surrounding utterances

> < : faster than surrounding utterances

° ° : softer than surrounding utterances

underlined : emphasis through volume, pitch or tone

: : preceding sound is markedly lengthened

.hh : audible breath

[…] : part of the interaction left out

↑ : rising intonation

↓ : falling intonation

English summary

Doctor-Patient Communication in Head-and-Neck Cancer Follow-up Consultations: The role of the Distress Thermometer and Problem List.

This thesis investigates the interaction between doctor, patient and sometimes companion in a corpus of scheduled head-and-neck cancer follow-up consultations in a cancer hospital in The Netherlands, with a focus on the effects of the introduction of the Distress Thermometer and Problem List (DT+PL) as a tool to further the discussion of psychosocial distress.

The **Introduction** presents the rationale for the study and the theoretical approaches used for analysis. Since psychosocial distress has a negative effect on health and healing, it is widely considered important to structurally include the discussion of psychosocial distress in follow-up. Since for various reasons this does not yet happen structurally, the DT+PL has been introduced to stimulate doctors and patients to include this topic in their discussions. The DT+PL consists of a Distress Thermometer and a Problem List. On the Distress Thermometer patients indicate their level of distress on a scale of 1-10, with 1 equalling negligible distress, and 10 extreme distress. On the Problem List patients can indicate 47 possible problem areas, 25 of which are physical, and 22 psychosocial. The DT+PL is meant to be discussed with patients' medical carer during the consultation.

Since quantitative research has yielded unclear and contradictory results on the effects of the DT+PL, this thesis will contribute a qualitative approach focussing on the insider perspective of the interactants. It makes use of a triangulated, discourse analytical approach, combining insights from ethnography of communication, conversation analysis and linguistic pragmatics – fields which have contributed widely to the analysis of medical interaction – to create a rich, in-depth picture of the interactions under study. The Introduction ends with the research questions that will be addressed.

Chapter 1 discusses the technical aspects of collecting, processing and analysing the data for this study. The data consist of video-recordings and transcriptions of 42 follow-up cancer consultations (a control group of 28 consultations without the use of the DT+PL, and an intervention group of 14 consultations with the use of the DT+PL); a video-recording and transcription of a training session on how to work with the DT+PL; video-recordings and transcriptions of the interviews with the four doctors and 42 patients involved

in the study; the filled-out DT+PLs of the 42 patients; and the patients' medical data. In the DT+PL group the patients filled out the DT+PL *before* the consultation and brought it with them for discussion. In the Control group patients filled it out *after* the consultation, so that neither the physician nor the patient was influenced by it during the interaction.

Chapter 2 discusses the follow-up head-and-neck cancer consultation as a speech event, making use of the SPEAKING model developed by Hymes (1977; further developed by Saville-Troike, 2003) to create an in-depth description of the parameters of the consultation that form the context of the interaction. Participants' orientation to the context influences the interaction: how they interpret what is being said, the relevance of topics, who can speak at what point, etc. (cf. Nøckleby, 2011). Since what people say and do depends on the context in which they find themselves, understanding the context is essential for the *analysis* of interaction.

The chapter details the Setting of the consultation (a scheduled, time-limited return visit to the hospital); the Participants and their roles (physician, patient and companion); the Ends or aims of the consultation (to monitor the patient for after-effects and recurrence, and to relieve their anxiety); the Act sequence (opening, anamnesis, physical examination, discussion of findings, advice/next steps, wrap-up and closing); the Key or mood (oriented towards wellness or distress); Instrumentalities (message forms including spoken interaction, computer files, notes, etc.); Norms (what can be said when and by whom); and Genre (medical interaction). All of these parameters influence each other and the way the interaction unfolds.

Chapter 3 discusses the 'How are you?' (HAY?) question, which is used in all but one of the Control group data as an interactional device to move to the business at hand of the consultation and start the anamnesis. Contrary to what is reported in research using English and American data, the patients in our Dutch data consistently interpret the HAY? question as a medical (rather than a phatic, social) inquiry. This seems due to the Dutch medical context, in which doctors have already completed three of the elements identified by Robinson (2013) as creating the transition from a social to a medical context (greeting, establishing identity, checking record) before they ask the HAY? question. An additional reason is the fact that the follow-up consultation is a typical return visit, and this is often referenced in the formulation of the HAY? question with the addition of phrases like 'in the meantime' or 'under the circumstances'. The more strongly the medical context has been created, the more likely a medical interpretation of the HAY? question.

Replies to the HAY? question are often seemingly contradictory (with a first positive gloss followed by a complaint), and show delay, hedging and disfluency. This indicates that the HAY? question is a complex question for the patient group under study: it always relates to the circumstances of just having had a bout with cancer, and it may not be clear whether it asks them to compare their situation to before they were ill, when they were ill, when they had just finished treatment, or when they last saw the doctor. Often patients give a first gloss indicating that on the whole they are doing OK, and continue with a 'but' followed by a complaint: they are still suffering from side-effects or after-effects.

Chapter 4 discusses the 'Key' or mood of the consultation; do we see an orientation towards wellness or distress? Both can be expected, since on the one hand the follow-up consultation takes place after treatment, when patients are expected to be getting/feeling better, but on the other hand they may (still) be suffering from – sometimes quite debilitating – side-effects, after-effects and anxiety. The data show a mixture of orientations to both wellness and distress. However, since distress is in the great majority of cases introduced into the discussions with delay, hedging and disfluencies, it would seem that the discussion of distress is discursively dispreferred.

Chapter 5 discusses how the introduction of the DT+PL affects the contextual parameters and the structure of the consultation. The introduction of a new Instrumentality (the DT+PL) into the consultation affects the Setting, the Participant roles, the Ends, and the Act Sequence. It adds an extra End or aim, in that the DT+PL has to be discussed, and with it any psychosocial issues that are mentioned in it. It changes the Participant roles, in that the patients have more agency (they can pre-nominate issues on the DT+PL, and so put them on the agenda for discussion in the consultation). Also, doctors in the DT+PL group pro-actively nominate emotional distress, which they did not do in the Control group consultations. The introduction of the DT+PL may affect the time element of the Setting, in that there is more to discuss, and thus more time-pressure on the consultation. It changes the Act sequence, in that there is an extra element on the agenda, a problem which the two doctors solve with different discursive strategies. The transition from opening to anamnesis is sometimes affected, when the DT+PL seems to usurp the place and function of the HAY? question, which is the standard device for opening anamnesis in the control group.

Chapter 6 investigates the discussion of psychosocial problems, both with and without the use of the DT+PL. Compared to the Control group, in the DT+PL group more psychosocial problems were discussed, but there are considerable differences between the two doctors. The average increase in problems discussed may be due more to the larger problem load of Dr A's patients, and to her (item-by-item) approach to discussing the DT+PL.

Still, just under 50% of the psychosocial problems patients had noted on the DT+PL remained undiscussed. This may be due to a variety of causes. First, in some consultations patients had indicated so many problems that it would be impossible to discuss them all within the scheduled time. Second, doctors and patients alike block the discussion of some topics: patients may not consider certain problems urgent enough to discuss, and doctors can discursively limit possible topics through the formulation of their questions, asking, for instance, if anything has changed, or if there are any new issues. Third, the design of the DT+PL does not filter out fossilised problems, issues that are not related to cancer, or issues that patient does not require help with, and so may not merit discussion.

Chapter 7 analyses how emotional problems are discussed, both in a context without the use of the DT+PL and with the use of the DT+PL. The DT+PL changes the epistemic status of the doctors relative to emotional problems from 'unknowing' to 'knowing'. This change in their epistemic status enables the doctors to proactively nominate emotional problems for discussion, which they did not do in the Control group.

In both conditions, doctor and patient together co-construct the relevance of topics for further discussion, with doctors relying on their medical expertise for their argumentation, and patients relying on a variety of sources, including information garnered from friends and relatives, the Internet and patient leaflets. In cases of disagreement – a possible face threatening act (Brown & Levinson 1987/2009), and interactionally dispreferred (Pomerantz, 1984) – this is formulated with indirectness strategies (delay, disfluency, hedging) to mitigate loss of face on the part of the participants involved.

Timing seems relevant to the discussion of emotional problems; emotional problems that are nominated late in anamnesis or after the physical examination seem to have a better chance of being discussed than if they are mentioned earlier (cf. Zhou et al., 2015).

Conclusions

The DT+PL changes doctors' epistemic status about patients' psychosocial problems from 'unknowing' to 'knowing'. As such, it seems to help doctors and patients to discuss emotional distress: a larger percentage of emotional problems is discussed, and the information in the DT+PL prompts doctors to initiate the discussion of such problems, which they did not do in the consultations without the DT+PL. Both patients' problem load and the way that doctors approach the discussion of the DT+PL seem to have an impact on the number of problems that are discussed.

Not all the problems that patients indicate on the PL are discussed. This may be due to various inherent barriers to the structural discussion of psychosocial/emotional distress: time pressure, the design of the DT+PL, which does not filter out problems that are less relevant for discussion, patients' reluctance to discuss issues that they do not deem relevant for this doctor in this consultation, and doctors' self-perceived lack of expertise in discussing psychosocial issues. Whether oncological surgeons and oncological radiologists are the medical carers of choice to monitor psychosocial distress in follow-up is a moot point. In many hospitals it is the oncological nurse that is responsible for this.

It should be borne in mind that the DT+PL is neither a list of items for which patients desire support, nor a complete list of patients' concerns: in the consultations patients raised many issues that they had not indicated on the PL, and there were many items on the PL that they had no desire to discuss or need help with.

The introduction of the DT+PL may necessitate some tweaking of the way the consultation is conducted. The HAY? question, which is an important starter question eliciting patients' self-assessment of their condition, may be impacted by the DT+PL. Doctors may wish to combine the embedding of the DT+PL and the HAY? question into the consultation in such a way that overlap is avoided, and patients are invited to share all the information that is relevant to them and to their physician. If the DT+PL is not discussed at the outset of the consultation, it may be useful to inform patients of the 'agenda' of the consultation and the place of the DT+PL in it. Useful ways into the discussion of the issues on the DT+PL might include asking patients what they most want to discuss, and whether they can cope or need extra help. To make sure that nothing has been left out it might be useful to ask whether there are any remaining questions or issues that they wish to talk about.

Nederlandse samenvatting

Doctor-Patient Communication in Head-and-Neck Cancer Follow-up Consultations: The role of the Distress Thermometer and Problem List.

Dit proefschrift onderzoekt de interactie tussen arts, patiënt en soms begeleider in een corpus van reguliere hoofd-halskanker follow-up consulten in een Nederlandse kankerkliniek, met speciale aandacht voor de effecten van de introductie van de Lastmeter als instrument om de bespreking van psychosociale problemen van patiënten in het follow-up traject na de behandeling te bevorderen.

De **Introductie** presenteert de achtergrond van de studie en de theoretische benadering. Er is brede consensus dat het belangrijk is om de psychosociale last van kankerpatiënten structureel in follow-up consulten te bespreken omdat psychosociale last een negatief effect heeft op gezondheid en herstel. Aangezien dit om uiteenlopende redenen niet structureel gebeurt, is de Lastmeter ingevoerd om artsen en patiënten te stimuleren dit onderwerp in hun gesprekken ter sprake te brengen. De Lastmeter bestaat uit de Lastmeter zelf en de Probleemlijst. Op de Lastmeter (die de vorm heeft van een thermometer) geven de patiënten op een schaal van 1-10 aan hoe hoog zij hun lastniveau ervaren. Op de Probleemlijst kan de patiënt 47 mogelijke probleemgebieden aankruisen, 25 fysieke en 22 psychosociale. Het is de bedoeling dat de Lastmeter met de patiënt wordt besproken tijdens het consult.

Kwantitatief onderzoek naar het effect van de Lastmeter heeft tot nu toe onduidelijke en tegenstrijdige resultaten opgeleverd. In dit proefschrift is daarom gekozen voor een *kwalitatieve* aanpak die zich richt op beschrijving en analyse van de interactie tijdens de consulten vanuit het perspectief van de insiders: de deelnemers in de sociale gebeurtenis zelf. Hierbij wordt gebruik gemaakt van een multidisciplinair theoretisch kader dat inzichten uit de etnografie van de communicatie combineert met onderzoeksmethoden uit de conversatie-analyse en taalkundige pragmatiek.

Hoofdstuk 1 bespreekt de technische aspecten van het verzamelen, verwerken en analyseren van de data voor de studie. De data bestaan uit video-opnamen van 42 follow-up hoofd-halskankerconsulten (een controlegroep van 28 consulten zonder gebruik van de Lastmeter, en een interventiegroep van 14 consulten met gebruikt van de Lastmeter); een video-opname van een trainingssessie in het gebruik van de Lastmeter; video-opnamen van interviews met de 4 artsen en 42 patiënten die deelnamen aan het onderzoek; de ingevulde Lastmeters van de 42 patiënten; en de medische gegevens van de patiënten. De patiënten in de Lastmetergroep vulden de Lastmeter in *voor* het consult en brachten het ingevulde document mee ter bespreking. De patiënten in de controlegroep vulden de Lastmeter in *na* het consult, zodat noch zij, noch hun arts erdoor werden beïnvloed tijdens het consult, maar de onderzoeker wel zicht had op de psychosociale problemen van de patiënt.

Hoofdstuk 2 bespreekt het follow-up hoofd-halskankerconsult als 'speech event'. Het gebruikt het SPEAKING-model[61] dat is ontwikkeld door Hymes (1977; verder ontwikkeld door Saville-Troike, 2003) om een diepgaande beschrijving te maken van de parameters van het consult die de context vormen van de interactie. Uitgangspunt hierbij is dat wat mensen zeggen en doen afhankelijk is van de context waarin ze zich bevinden. De context beïnvloedt bijvoorbeeld hoe zij interpreteren wat er wordt gezegd, welke gespreksonderwerpen als relevant worden beschouwd, wie op welk punt spreekrecht heeft, enz. (zie Nøckleby, 2011). Daarom is begrip van de context ook van belang voor de *analyse* van interactie.

Het hoofdstuk beschrijft de 'Setting' van het consult (een regelmatig terugkerend, gepland bezoek aan het ziekenhuis met een vastgestelde tijdsduur); de 'Participanten' en hun rollen (arts, patiënt en begeleider); de 'Ends' of doelen van het consult (om patiënten te volgen met het oog op mogelijke bijverschijnselen en terugkeer van de aandoening, en om ongerustheid weg te nemen); de 'Act sequence' of standaard handelingen (opening, anamnese, lichamelijk onderzoek, bespreking van bevindingen, advies/volgende stappen, afronding en afsluiting); de 'Key' of toon van het consult (georiënteerd op welbevinden of last/distress); de 'Instrumentalities' of vormen van communicatie (bijv. gesproken interactie, computer files, aantekeningen, etc.); de 'Normen' (wat door wie wanneer gezegd kan worden); en het 'Genre' (medische interactie). Al deze parameters beïnvloeden elkaar en de manier waarop de interactie zich ontvouwt.

Hoofdstuk 3 bespreekt de 'Hoe gaat het met u?' (HAY?) vraag, die in vrijwel alle data uit de controlegroep wordt gebruikt als openingsvraag aan het begin van de anamnese. In tegenstelling tot bevindingen uit veel Amerikaans en Brits onderzoek, interpreteren de Nederlandse patiënten in de data de HAY? vraag consequent als een medische (in plaats van een sociale, fatische) vraag. Dit lijkt samen te hangen met de praktijk in Nederlandse ziekenhuizen, waar de arts de patiënt gewoonlijk ophaalt uit de wachtkamer. Zodoende zijn drie van de elementen waarmee artsen de overgang van de sociale naar de medische

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[61] SPEAKING is een acroniem voor de door Hymes onderscheiden contextuele parameters: Setting, Participants, Ends, Act sequence, Key, Instrumentalities, Norms en Genre.

context creëren (groeten, identiteit vaststellen en het dossier checken; Robinson, 2013) al voltooid voor de HAY? vraag wordt gesteld. Verder is het follow-up consult typisch een vervolg-visite. Hieraan wordt vaak gerefereerd in de formulering van de HAY? vraag, met frasen zoals 'in de tussentijd' en 'in de omstandigheden'. Ook dit versterkt de medische context. De data laten zien dat een sterke medische context het waarschijnlijker maakt dat de HAY? vraag een medische interpretatie krijgt.

Antwoorden op de HAY? vraag in de data lijken zichzelf vaak tegen te spreken (met een positieve eerste reactie gevolgd door een klacht) en gaan gepaard met vertraging, aarzeling en disfluency. Dit geeft aan dat de HAY? vraag een ingewikkelde vraag is voor de patiëntengroep in deze studie. De vraag is altijd gerelateerd aan het feit dat de patiënt net kanker heeft gehad, en het kan lastig zijn te bepalen of zij om een vergelijking vraagt met de situatie van voor de ziekte, tijdens de ziekte, net na de behandeling, of bij de vorige visite aan de arts. Patiënten geven daarom vaak een complex antwoord: zij geven dan in een eerste reactie aan dat het in grote lijnen goed met hen gaat, en gaan verder met 'maar' gevolgd door een klacht: zij hebben nog last van bijwerkingen en nawerkingen.

Hoofdstuk 4 bespreekt de 'Key' of toon van het consult; zien we een oriëntatie op welbevinden of op distress/last? Beide kunnen worden verwacht: het follow-up-consult vindt plaats na behandeling, zodat de verwachting is dat het beter gaat met de patiënt. Artsen gebruiken voor een oriëntatie op welbevinden bijvoorbeeld 'no problem' vragen, en een positief lopend commentaar tijdens het lichamelijk onderzoek, terwijl patiënten bijvoorbeeld hun symptomen minimaliseren, en aangeven dat ze aan een gezonde levensstijl werken. Anderzijds kan de patiënt (nog) last hebben van – soms zeer ingrijpende – nawerkingen, bijwerkingen en spanningen. Om de arts te oriënteren op hun distress, gebruiken patiënten o.a. hyperbolen en nadrukkelijke intonatie. De artsen responderen door probleemgerichte vervolgvragen te stellen en geven waar relevant probleemgericht commentaar tijdens het lichamelijk onderzoek. De data laten een mix van oriëntaties zien op zowel welbevinden als distress/last. Aangezien distress/last in een ruime meerderheid van de gevallen wordt geïntroduceerd met vertraging, aarzeling en hapering/disfluency lijkt het erop dat het bespreken van distress/last discursief niet geprefereerd is.

Hoofdstuk 5 bespreekt hoe de introductie van de Lastmeter de contextuele parameters en de structuur van het consult beïnvloedt. De introductie van een nieuwe Instrumentality (de Lastmeter) heeft invloed op de Setting, de rollen van de Participanten, de Ends en de Act sequence. Het voegt een extra End of doel toe, in die zin dat de Lastmeter moet worden besproken, en daarmee de psychosociale issues die erin zijn aangegeven. Het verandert de rollen van de Participanten, in die zin dat de patiënten meer 'agency' hebben (zij kunnen problemen prenomineren in de Lastmeter, en die zo op de agenda zetten voor bespreking tijdens het consult). Daarnaast blijkt uit de data in de Lastmetergroep dat de artsen proactief emotionele distress nomineren, iets wat zij niet doen in de controlegroep. De introductie van de Lastmeter kan het tijdelement van de Setting beïnvloeden, aangezien er meer te bespreken is en er dus grotere tijdsdruk op het consult ontstaat. Het verandert de Act sequence, aangezien er een extra element op de agenda staat. Ook wordt de overgang tussen opening en anamnese soms beïnvloed; de Lastmeter neemt soms de plek en functie over van de HAY? vraag, waarmee de artsen in de controlegroep normaliter de anamnese openen.

Hoofdstuk 6 onderzoekt de bespreking van psychosociale problemen in de data, zowel met als zonder het gebruik van de Lastmeter. In de Lastmetergroep worden gemiddeld meer psychosociale problemen besproken dan in de controlegroep, maar er zijn grote verschillen tussen de twee artsen: de gemiddelde toename in besproken problemen zou verband kunnen houden met de grotere probleemlading van de patiënten van Dr A, en met haar punt-voor-punt aanpak van de bespreking van de Lastmeter.

Ondanks de toename in de Lastmetergroep blijft ook hier iets minder dan 50% van de psychosociale problemen die de patiënten op de Lastmeter hebben aangegeven, onbesproken. Hiervoor wordt een aantal mogelijke oorzaken gevonden. Ten eerste, in een aantal consulten hadden de patiënten zoveel problemen aangekruist, dat het onmogelijk zou zijn ze alle in de geplande tijd te bespreken. Ten tweede, het ontwerp van de Lastmeter bevat geen filter; problemen die misschien minder relevant zijn voor bespreking tijdens het consult, zoals oude, gefossiliseerde, niet aan kanker gerelateerde problemen en problemen waarvoor de patiënt geen hulp wil, kunnen allemaal worden aangekruist. In verband hiermee blokkeren artsen en patiënten de bespreking van sommige onderwerpen. Patiënten kunnen van mening zijn dat bepaalde problemen niet urgent genoeg zijn om te bespreken, en artsen kunnen mogelijke onderwerpen discursief beperken door te vragen of er iets is veranderd, of er nieuwe problemen zijn, enz.

Hoofdstuk 7 analyseert hoe emotionele problemen worden besproken in consulten met en consulten zonder het gebruik van de Lastmeter. De Lastmeter verandert de epistemische status van de artsen ten aanzien van de emotionele problemen van de patiënt van ‘niet-wetend’ naar ‘wetend’. Die verandering in epistemische status maakt het mogelijk voor de arts om emotionele problemen proactief te nomineren voor bespreking, iets wat zij niet doen in de controlegroep.

Als problemen eenmaal zijn genomineerd, co-construeren arts en patiënt in beide condities samen of een onderwerp relevant is voor verdere bespreking. Hierbij bouwen de artsen voor hun argumenten op hun medische expertise, en patiënten op diverse bronnen, waaronder informatie verkregen van vrienden en familie, het Internet, en patiëntenfolders. Als participanten het niet eens zijn – een mogelijke ‘face threat’ (Brown & Levinson 1987/2009) en interactioneel ‘dispreferred’ (Pomerantz, 1984) – wordt dit geformuleerd met indirectheidstrategieën (vertraging, aarzeling en hapering/disfluency) om gezichtsverlies voor alle partijen te beperken.

Timing lijkt relevant bij de bespreking van emotionele problemen; emotionele problemen die tegen het eind van de anamnese of na het lichamelijk onderzoek worden genomineerd hebben een betere kans om besproken te worden dan problemen die eerder worden benoemd (zie ook Zhou et al., 2015).

Conclusies

De Lastmeter verandert de epistemische status van artsen ten aanzien van de psychosociale problemen van patiënten van ‘niet wetend’ naar ‘wetend’. Dit lijkt artsen en patiënten te helpen om emotionele problemen te bespreken: er wordt een groter percentage emotionele problemen besproken, en de informatie in de Lastmeter stimuleert de artsen om de bespreking van deze problemen te initiëren, iets dat ze in de controlegroep niet doen. De probleemlading van patiënten en de manier waarop artsen de bespreking van de Lastmeter aanpakken lijken echter beide invloed te hebben op het aantal problemen dat wordt besproken.

Niet alle problemen die patiënten aangeven op de probleemlijst worden besproken. Deels is hiervoor het ontwerp van de Lastmeter verantwoordelijk, omdat die geen onderscheid maakt tussen verschillende typen last. Deels wordt dit veroorzaakt door diverse inherente barrières voor de structurele bespreking van psychosociale/emotionele last: tijdsdruk; de terughoudendheid van patiënten om zaken te bespreken die zij voor deze arts en voor dit consult niet relevant achten; en de eigen inschatting van de artsen dat het hun aan de relevante expertise ontbreekt om zulke problemen te bespreken. Of oncologische chirurgen en oncologische radiologen de meest geschikte medische verzorgers zijn om psychosociale distress te monitoren is een betwistbaar punt. In veel ziekenhuizen wordt deze taak door oncologisch verpleegkundigen vervuld.

De introductie van de Lastmeter veroorzaakt een interactioneel dilemma voor de arts bij de opening van het consult: de Lastmeter interfereert met de HAY? vraag, die patiënten verzoekt om een eigen beoordeling te geven van hun toestand. Artsen zouden ertoe kunnen overgaan om de Lastmeter en de HAY? vraag zo in te bedden dat overlap wordt vermeden en dat patiënten worden uitgenodigd om alle informatie te delen die relevant is voor henzelf en voor de arts. Als de Lastmeter niet aan het begin van het consult wordt besproken, kan het nuttig zijn om de patiënt te informeren over de 'agenda' van het consult en de plaats van de Lastmeter daarin. Nuttige strategieën om de Lastmeter te bespreken zijn vragen als 'wat zoudt u het liefst willen bespreken?', 'lukt het om met de nieuwe situatie om te gaan?', en 'zijn er dingen waarbij u extra hulp kunt gebruiken?'. Om ervoor te zorgen dat niets is vergeten kunnen slotvragen nuttig zijn als 'heeft u nog andere vragen?', of 'zijn er nog zaken die u wilt bespreken?'.

Tenslotte is het goed om te bedenken dat de Lastmeter geen lijst van problemen is waarvoor patiënten hulp zoeken, noch een volledige lijst van de problemen van de patiënt: in de consulten brachten de patiënten een groot aantal problemen ter sprake die zij niet op de probleemlijst hadden aangekruist, en er waren veel items op de probleemlijst aangekruist die zij niet wilden bespreken en waarvoor zij geen hulp wilden.