

**Communicating with older cancer patients:
impact on information recall**

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Communicating with older cancer patients: impact on information recall

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Contents

Chapter 1	Introduction	9
Chapter 2	Patient education about treatment in cancer care: an overview of the literature on older patients' needs	29
Chapter 3	Does age really matter? Recall of information presented to newly referred patients with cancer	53
Chapter 4	Recall in older patients: measuring memory for medical information	73
Chapter 5	Emotional and informational patient cues: the impact of nurses' responses on recall	93
Chapter 6	The role of companions in aiding older cancer patients to recall medical information	113
Chapter 7	Summary and discussion	135
Appendix A	Overview of the overarching study	163
Appendix B	Interventions to improve recall of medical information in cancer patients: a systematic review of the literature	167
References		195
Samenvatting		217
Dankwoord		225
Curriculum Vitae		229

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1

Introduction

Introduction

“Selection is the very keel on which our mental ship is built. And in the case of memory its utility is obvious. If we remembered everything, we should on most occasions be as ill off as if we remembered nothing.” (William James, 1890, p 680)

This quote by William James illustrates that it is virtually impossible to remember all the information and events we encounter in daily life; even under normal circumstances our information processing capacity is limited. Imagine the situation that your doctor has just told you that you have cancer and need to undergo treatment. Imagine further that, on top of all that, you are 75 years old and your memory is not as good as it used to be. It is not unreasonable to assume that under these circumstances, it is even more difficult to take in and remember what people tell you. What older patients with cancer remember from medical consultations is the main thread throughout this thesis. In the following chapters we will identify factors that are important in the communication with older cancer patients with a focus on information recall. Before doing so, we will touch upon some general topics to provide relevant background and briefly outline the issues that are addressed in this thesis. Throughout the word ‘clinician’ is used to refer to all the relevant members of the health care team.

Communication in cancer care

The news of a life threatening cancer diagnosis is very distressing for most people. Cancer patients commonly experience feelings of uncertainty about the future and high levels of fear and anxiety (Anderson et al., 2008; Jacobsen & Jim, 2008; Schofield et al., 2003). Not surprisingly, patients often are overwhelmed and upset when they talk to their clinician (Epstein & Street, 2007), which may be enhanced by threatening information, for example, about the prognosis or treatment (Kessels, 2003; Peters, Lipkus, & Diefenbach, 2006; Van Zuuren & Wolfs, 1991). At the same time, patients are asked to make difficult treatment decisions and are presented with complex information on side effects and treatment options that may impact on them in a profound way. The importance of good patient-clinician communication is widely

acknowledged and may be even more significant in the emotionally charged and informationally complex cancer setting. Patient-clinician communication in cancer care may serve several functions. Two of these functions are to help patients: 1) manage the side effects of the disease and treatment, and 2) understand and remember the complex information that they are faced with (Epstein & Street, 2007).

Many patients report that undergoing chemotherapy treatment is one of the hardest aspects of having cancer (e.g. Mitchell, 2007). That is not surprising as chemotherapy treatment can cause debilitating side effects. These side effects vary greatly from person to person, according to the type of drugs, and from one treatment period to the next (Carelle et al., 2002; Love, Leventhal, Easterling, & Nerenz, 1989; Mulders, Vingerhoets, & Breed, 2008). They can include fatigue, pain, nausea and/or vomiting¹, diarrhoea, constipation, hair loss, immunosuppression and mouth ulcers but also anxiety about the treatment and worry about the effect it has on their family life, work and social activities (Carelle et al., 2002; Griffin et al., 1996; Henry et al., 2008; Mitchell, 2007; Mulders et al., 2008; Uitterhoeve, Duijnhouwer, Ambaum, & van Achterberg, 2003). Dr Anna Donald, a medical doctor who kept a blog at the British Medical Journal website about her experiences as a cancer patient, described it very eloquently as:

“I’ve got lots of metaphors for it [chemotherapy]: a small elephant that sits on you, then trundles off, only to absent-mindedly turn around and sit on you again. As the days pass, the elephant becomes a donkey, and finally a small dog. Then you feel a bit better. Other times, chemo is like being immersed in loud white noise. You just have to wait until it’s over.” (8th May, 2008, <http://blogs.bmj.com/bmj/2008/05/19/anna-donald-confessions-of-a-chemo-veteran/>, accessed 10th December 2008).

Fortunately, clinicians can often mediate the distressing side effects by prescribing medication (e.g. anti-nausea medication) or adjusting the chemotherapy dosage.

¹ As a result of developments in chemotherapy and the introduction of anti-emetic regimens vomiting is no longer a prominent side effect (Carelle et al., 2002; Henry et al., 2008).

More importantly, clinicians can promote patients' ability to manage side effects themselves and seek appropriate care when needed by educating them and giving them suitable recommendations (Epstein & Street, 2007; McIlfatrick, Sullivan, McKenna, & Parahoo, 2007; Schofield et al., 2008). The importance of good patient education about chemotherapy treatment is underscored by the fact that people with cancer express a strong desire for information on self-care (Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Sanson-Fisher et al., 2000). Moreover, chemotherapy is most commonly given on an outpatient basis and patients have to manage most side effects at home (McIlfatrick et al., 2007; Schofield et al., 2008). Nurses play an important role in educating patients undergoing chemotherapy treatment (Schofield et al., 2008; Uitterhoeve et al., 2003; Verity, Wiseman, Ream, Teasdale, & Richardson, 2008). The role of nurses is expected to become even more important in the future with the emergence of nurse specialists and doctors increasingly sharing responsibilities with nurses (Fitzsimmons et al., 2005). By providing patients with information and addressing their emotional concerns, nurses might facilitate the patients' adaptation to the treatment (Butow, Brown, Tattersall, & Dunn, 2002; Ream & Richardson, 1996). In The Netherlands, after consultation with oncologist, most patients see a specialized oncology nurse who educates them about their treatment (Uitterhoeve et al., 2007).

Recall of information

To speak with Silberman (2008): *“even the best treatment recommendations can be rendered useless by poor patient recall”*. In other words, when patients do not remember the recommendations, they are unlikely to act accordingly. Indeed, many health psychology and health communication theories consider knowledge, and thus recall, as a fundamental precondition for influencing behaviour (Abraham & Michie, 2008; Kiviniemi & Rothman, 2006; Maibach & Cotton, 1995). For example, according to Ley's Cognitive Model (1982), how well patients recall the advice given to them by health professionals largely determines whether patients follow the advice given. In addition, recall has been linked with improved treatment adherence and health outcomes (Flocke & Stange, 2004; Ley, 1988; Schillinger et al., 2003). Unfortunately, it is known that cancer patients forget substantial amounts of the information presented

in the consultation with reported recall scores ranging from 25%-80% (Brown, Butow, Dunn, & Tattersall, 2001; Dunn et al., 1993; Gabrijel et al., 2008; Leighl, Gattellari, Butow, Brown, & Tattersall, 2001). Indeed, a recent study indicates that patients spent a considerable amount of time in the hospital to treat side effects of chemotherapy treatment that could have been avoided if the patient had known and remembered the necessary precautions (Henry et al., 2008). One way a clinician can enhance the likelihood that patients will recall what is discussed in the consultation is by tailoring communication.

Tailored communication takes into account the characteristics of the individual patient, including his or her needs, preferences, wishes, values, beliefs, emotions, cognitive resources and context (Epstein & Street, 2007; Kruglanski et al., 2006; Peters et al., 2006; Rimer & Kreuter, 2006). According to Rimer and Kreuter (2006), tailoring makes information more relevant to the patient, will enhance the receptivity for the information presented and subsequently increase the motivation to process the information. This notion is in line with Petty and Cacioppo's Elaboration Likelihood Model of persuasion (ELM; Petty, Goldman, & Cacioppo, 1981; Petty, Wegener, & Fabrigar, 1997) that asserts that people will process information more actively and elaborately when it is personally relevant (see also Kruglanski et al., 2006 for an adaptation of the ELM and an application in the cancer context). Enhanced information processing will result in better recall as it increases the chances that information is encoded and stored in memory (Craik & Lockhart, 1972). Experimental studies have shown that giving tailored information indeed improves recall of medical information (Morrow et al., 2005; van der Meulen, Jansen, van Dulmen, Bensing, & van Weert, 2008). The way medical information recall is conceptualised differs greatly among studies and it is often used interchangeably with terms such as understanding, comprehension, retention, awareness or recognition (Sand, Loge, & Kaasa, 2008). In this thesis, the Oxford English Dictionary definition of recall '*to recollect, remember*' will be used.

Communication with older cancer patients

For older patients it may be even more difficult to remember the information provided in the consultation, which has consequences for their physical health

and outcomes (Stewart, Meredith, Brown, & Galajda, 2000). Furthermore, the incidence of cancer is often age-dependent and the population is rapidly aging, implying that an increasing number of older people need cancer treatment (Pasetto et al., 2007). In the Netherlands, more than 55 percent of all cancer diagnoses occur among the 15% of the population that is 65 years or older (CBS (Statistics Netherlands), 2008; KWF Kankerbestrijding (the Dutch Cancer Society), 2004), hereinafter referred to as ‘older cancer patients’.

It is generally assumed that there are differences between cancer in older and younger adults. This has resulted in the emergence of a relatively new field in oncology: geriatric oncology (Cohen, 2007; Lichtman, Balducci, & Aapro, 2007). Geriatric oncology starts at age 65, which is, of course, an arbitrary definition (Aapro & Johnson, 2007). As eloquently stated by Adelman and colleagues (2000): “nothing magically occurs at the chronological age of 65 that marks a person as older”. Until recently, older cancer patients have been systematically underrepresented in or excluded from clinical trials, and when included they represent the minority of very fit elderly (Hutchins, Unger, Crowley, Coltman, & Albain, 1999; Lewis et al., 2003; Tallarico, Figueiredo, Goodman, Kreling, & Mandelblatt, 2005; Yee, Pater, Pho, Zee, & Siu, 2003). However, based on an extrapolation of factors that are important in predicting mortality in the general geriatric population, areas have been identified that might predict outcomes in older cancer patients including functional status, comorbidity, cognition, unintentional weight loss, psychological state and social support, and concomitant medication use (e.g. Extermann & Hurria, 2007; Repetto & Balducci, 2002; Rodin & Mohile, 2007). Although in the past, older cancer patients have been undertreated, it is now generally acknowledged that it is important to identify the vulnerable or frail patients, rather than basing disease management on chronological age (Balducci, 2007).

A prerequisite for tailoring information is knowledge of the individual patient’s characteristics. In the case of older cancer patients, this is not straightforward because older cancer patients not only have been excluded from clinical trials but are also underrepresented in psychosocial studies (Chouliara, Kearney, Stott, Molassiotis, & Miller, 2004; Sanderman, Coyne, & Ranchor, 2006). As a result, there is a paucity of information about how cancer and chemotherapy treatment affects the older patient population, and what older cancer

patient's specific needs, preferences and issues are.² This leaves clinicians with the difficult task of 'bridging the gap' between evidence-based but general information about chemotherapy treatment and the specific needs and issues of the older cancer patient (Bensing, 2000).

Age differences in communication and recall

All patients are different, and this is especially true for older patients as people become more heterogeneous with age. At the same time, aging is strongly associated with cognitive, physical, psychological, and social changes. These changes may have either a direct or indirect effect upon how older cancer patients communicate with clinicians and remember the information presented in the consultation (Brown & Park, 2003; Greene & Adelman, 2003; Hess, 2005; Kessels, 2003; Nussbaum, Baringer, & Kundrat, 2003; Roter, 2000).

The life-span model of Selection, Optimization and Compensation

One of the leading theories of aging is the life-span model of Selection, Optimization and Compensation (SOC; Baltes & Baltes, 1990). Simplified, this model asserts that aging is characterized by both gains and losses and that individuals can age successfully when they adapt their behaviour in response to age-related changes. Adaptive behaviours include: *selecting* goals you want to pursue, *optimizing* the necessary resources (e.g. time and effort) to engage in these goals and *compensate* (e.g. by asking others for help) if you encounter losses that were relevant to achieving your goal (Baltes & Carstensen, 1996; Baltes, 1997; Baltes & Baltes, 1990). The SOC model argues for a multi-dimensional approach when studying age related processes. In this thesis, we therefore attempt to address a constellation of factors that may influence communication with the older cancer patient and impact upon subsequent

² Since the start of this thesis there has been a steep increase in interest in the older cancer, as illustrated by a special issue in the Journal of Clinical Oncology (Vol 25, No 14, May 2007), The European Journal of Cancer (Volume 43, Issue 15, October 2007), the development of a EORTC Quality of Life module for the assessment of QOL in the Elderly patient with cancer (ELDxx; http://groups.eortc.be/qol/qolg_projects.htm#elderly; accessed 7th December 2008), the rise of International Society of Geriatric Oncology (SIOG) and the development of curricula for nurses by the European Oncology Nursing Society (EONS) http://www.cancerworld.com/CancerWorld/moduleStaticPage.aspx?id=1547&id_sito=2&id_stato=1; accessed 7th December 2008 and the Dutch Oncology Nursing Society (VvOV) <http://www.leermenu.nl/>; accessed 7th December 2008.

patient recall (Blank & Bellizzi, 2008; Hess, 2005; Nussbaum et al., 2003). In this introduction we will provide some background on the relevant changes that coincide with aging.

Age differences in cognitive performance and beliefs about memory and cognition

Evidently, cognitive decline increases with age and may thus effect patient-clinician communication and subsequent patient recall directly. Aging has been associated with decreases in speed of information processing (Salthouse, 1996), working memory performance (i.e. the amount of information a person can simultaneously process and store in consciousness; Bopp & Verhaeghen, 2005; Grady & Craik, 2000) and problems in inhibitory functioning (i.e. the ability to direct attention away from irrelevant information) (Darowski, Helder, Zacks, Hasher, & Hambrick, 2008). Age decline is more prominent in tasks requiring effortful processing such as recall tasks, whereas tasks relying predominantly on automatic processes such as recognition tasks remain largely unaffected themselves (Brown & Park, 2003). Further, older adults also have lower self-efficacy beliefs about their memory and cognitive function than do younger adults; this may influence their memory performance (Hess, 2005; Valentijn et al., 2006).

Experimental research largely confirms the theoretical models of cognitive aging as an overview by Brown and Park (2003) shows. That is, compared with younger adults, older adults have more problems comprehending information on prescription drug labels, materials on advanced medical directives, and have greater difficulty comprehending and recalling medical warnings. On the other hand, older adults are relatively good in performing well-practiced behaviours such as remembering to take medication regularly. However, an early overview of studies on recall of medical information by patients shows inconsistent effects of age (Ley, 1988). More recent studies also yield some contradictory findings, e.g. some report no significant relation between age and recall (Brown et al., 2001; Hayes & Buffum, 2001; Kumana, Ma, Kung, Kou, & Lauder, 1988; Leighl et al., 2001; Logan, Schwab, Salomone, & Watson, 1996; Middleton, Gattellari, Harris, & Ward, 2006) whereas others do (Butow, Brindle, McConnell, Boakes, & Tattersall, 1998; Gattellari, Butow, Tattersall, Dunn, & MacLeod, 1999; Howlader et al., 2004; Lavelle-Jones, Byrne, Rice, &

Cuschieri, 1993; Murdoch & Wilt, 1997; Olver, Turrell, Olszewski, & Willson, 1995; Pesudovs, Luscombe, & Coster, 2006; Rost, Roter, Bertakis, & Quill, 1990; Rushford et al., 2007). Despite the established effect of age on cognitive processing, the above studies show that the relation between patient age and recall of medical information is not unequivocal.

The heterogeneity of reported age-differences in recall may be partly due to differences in patient sample and study characteristics. Firstly, in accordance with a life-span perspective of aging, some older patients may adapt their behaviour to deal with these declines thereby counteracting the relation between older age and cognitive decline (Hanoch, Wood, & Rice, 2007; Hess, 2005). Secondly, the differences between older and younger patients may depend on the recall assessment method used. The commonly observed patterns of decline suggest that older patients are more impaired on recall tasks and open-ended questions compared with recognition tasks or multiple-choice questions (Brown & Park, 2003; Hess, 2005). Thirdly, differences in disease characteristics and general health are likely to be of importance (Hess, 2005). This means that chronological age may not be the best predictor of patient outcomes, as also suggested by the geriatric oncology literature (Balducci, 2007), and other factors may influence recall over and above the effect of age. Finally, educational attainment and gender play an important role because they may influence patient-clinician communication in addition to recall (Hall, Irish, Roter, Ehrlich, & Miller, 1994; Ley, 1988). We will further elaborate on these issues in the following paragraphs and in Chapter 3, 5 and 6.

Age differences in health

Not only is aging associated with cognitive decline, health problems are also more common as people get older. Firstly, older adults are more likely to experience auditory and visual problems (Valentijn et al., 2005). Secondly, the accumulation of health problems later in life may result in poorer general health and a higher likelihood of disease in older adults. As a consequence, there is a clear increase in comorbidities and polypharmacy with age (Delafuente, 2003; Gijzen et al., 2001; Satariano & Silliman, 2003; Weiss, Boyd, Yu, Wolff, & Leff, 2007). To add, older adults may have functional limitations and problems with activities of daily living, such as getting dressed or using the toilet, and instrumental activities of daily living, like preparing

meals and taking medication (Miller, Rejeski, Reboussin, Ten Have, & Ettinger, 2000). These factors may complicate older cancer patients' recall directly and indirectly.

General health problems such as chronic pain, cardiovascular disease and diabetes are associated with cognitive problems (Brown, Glass, & Park, 2002; Verhaeghen, Borchelt, & Smith, 2003), and may therefore directly decrease the amount of information patients remember from the consultation. These effects may be even more pronounced when patients undergo chemotherapy treatment, as it potentially has an impact on cognitive function (Hurria et al., 2006). Physical health may also influence recall indirectly because when the patient is physically frailer, the consultation may be more taxing. In addition, most available information about chemotherapy treatment focuses on the single-disease, cancer, and may therefore not apply for older cancer patients with multiple diseases (Weiss et al., 2007). For instance, dietary recommendations may be different if the older cancer patient also has diabetes. Against this background, it can be expected that communication with older cancer patients and their subsequent recall may be problematic. On the other hand, younger cancer patients with a more serious condition or poorer health may experience similar difficulties. We will address these issues in Chapter 3.

Psychological age differences

The above suggest that cancer patients' recall of the consultation may be influenced by age differences in 'cold' aspects such as cognition and physical health. Yet, age differences in recall may also determine 'hot' aspects such as goals, needs and emotions (see also Hess, 2005). There is evidence in the literature that these aspects of behaviour change with age (Carstensen, Isaacowitz, & Charles, 1999; Ebner, Freund, & Baltes, 2006; Gross et al., 1997) and influence information processing, cognitive performance and memory (Forgas, 1995; Hanoch et al., 2007; Peters et al., 2006). Developmental changes in goals, needs and emotions may influence recall in three ways: 1) patients are more likely to put effort in tasks that are consistent with personal goals and preferences (Petty et al., 1981; Petty et al., 1997), 2) needs and goals may influence how patients process information and what they attend to (Forgas, 1995; Hanoch et al., 2007; Peters et al., 2006), and 3) emotional

distress in cancer patients may influence their ability to engage in information processing (Kessels, 2003; Pickersgill & Owen, 1992).

Goals, needs and preferences

In the beginning of this paragraph we described how, according to the SOC model, one way of dealing with cognitive and physical decline is by selecting goals that you want to pursue (Baltes, 1997; Baltes & Baltes, 1990). As older adults experience more decline, they allocate their resources more judiciously compared with younger adults. They are therefore more selective in the tasks they engage in and prefer to invest in goal-relevant activities (Hess, 2005). This means that recall in older cancer patients is expected to benefit even more from information that is relevant for their situation and tailored to their needs. Also, when people age they shift the orientation of their goals from knowledge- or future- related goals, such as acquiring new information, to emotion-related goals, like spending quality time with loved ones (Carstensen et al., 1999). This means that older cancer patients may be less likely to desire information about their illness and treatment than younger patients.

Although research on the specific perspectives of older cancer patients is limited, it seems to be in line with this proposition. Whilst cancer patients in general express a high need for information, this is more prevalent in younger patients than in older patients (Jenkins, Fallowfield, & Saul, 2001; Rutten et al., 2005). Not only may the preferred amount of information differ according to age, older patients may also prefer information with a different content. Perceptions and meaning of cancer are different for older patients compared to younger patients. The current cohort of older cancer patients grew up in a time when cancer was seen as a death sentence and was not talked about openly (Greene & Adelman, 2003). Even though treatments are more successful now and people with cancer live increasingly longer, older patients may hold on to their earlier, more fatalistic, perceptions (Blank & Bellizzi, 2008; Greene & Adelman, 2003; Pinguart & Duberstein, 2004). The specific needs of older cancer patients surrounding treatment have not been systematically investigated and more research is clearly required. We will address this issue in Chapter 2.

Emotion regulation and emotional distress

Older cancer patients may be less distressed and anxious during cancer consultations than younger cancer patients. Firstly, older adults are better able to regulate their emotions and experience more positive and less negative emotions (Gross et al., 1997). Secondly, older adults are less likely to experience competition between roles (e.g. combining work with caring for children), and health threats such as cancer are more common later in life (Berg & Upchurch, 2007; Nerenz, Love, Leventhal, & Easterling, 1986). Older persons may therefore come to terms with having cancer more easily. In fact, several studies report that cancer and its treatment has a greater psychological impact on younger than older patients (Blank & Bellizzi, 2008; Ganz, Lee, Sim, Polinsky, & Schag, 1992; Nerenz et al., 1986; Sanson-Fisher et al., 2000).

In terms of the SOC model, improved emotion regulation and decreased emotional distress may be a compensation mechanism to counteract the effects of loss in cognitive resources. Especially since the emotional distress that many cancer patients experience during the consultation is likely to hamper recall (Christianson, 1992; Easterbrook, 1959; Kessels, 2003; Wessel, van der, & Merckelbach, 2000). That said, empirical studies on processing of medical information show inconsistent results. Some report a curvilinear or inverted U shape relationship between emotional distress and recall, where people who experience moderate anxiety recall more than those of low or high anxiety (Ley, 1988; Pickersgill & Owen, 1992). Others found an increase in recall with anxiety (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999; Ley, 1988). As such, increased emotion regulation with age may influence information recall in older cancer patients by diminishing the negative impact of distress on information recall. This topic will be touched upon in Chapter 3 and 5.

Age differences in communication

Patient-participation and information exchange

Both patients and clinicians have expectations regarding their respective roles and involvement in the consultation (Krupat et al., 2000). The expectations that older adults have of the patient-clinician relationship may be different

from younger patients and based on a more paternalistic model with a passive patient role (Greene, Adelman, Friedmann, & Charon, 1994; Jenkins et al., 2001; Pinguart & Duberstein, 2004; Roter, 2000). As a result, some older patients may deem it inappropriate to ask their clinician questions. In terms of the SOC model, older cancer patients may compensate for reductions in cognitive capacity and health by asking fewer questions during the consultations. Alternatively, older patients may participate less in the consultation because gathering information about their disease is not their prime goal (Lockenhoff & Carstensen, 2004).

Empirical studies on the effect of patient characteristics on communication have yielded mixed results. Some report that older patients indeed participate less actively in consultations and ask fewer questions (Beisecker, 1996; Eggly et al., 2006; Siminoff, Graham, & Gordon, 2006), whereas according to others participation is not related to age (Street, Gordon, Ward, Krupat, & Kravitz, 2005; Street & Millay, 2001). Clinicians, on the other hand, show older patients less encouragement to participate actively or they may use patronizing talk (Brown & Draper, 2003; Caris-Verhallen, Kerkstra, & Bensing, 1997; Gattellari, Butow, & Tattersall, 2001), which can negatively influence older patients' perceptions of their own ability to take part in the consultation. Furthermore, clinicians seem to provide older patients with less information than younger patients and older patients seek less information themselves (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Leigh et al., 2001; Reed, Mikels, & Simon, 2008).

Participation and information giving may influence recall in two ways. Firstly, patients who are actively involved in the consultation are expected to be better able to direct the information flow, understand the information and consequently recall more (Brown et al., 2001; Dimoska, Tattersall, Butow, Shepherd, & Kinnersley, 2008; Siminoff, Ravdin, Colabianchi, & Sturm, 2000; van der Meulen et al., 2008). Secondly, a greater proportion of the information is forgotten when a greater quantity of information is presented (Ley, 1988; Rost & Roter, 1987). In Chapter 3, we will explore age differences in question asking and patient involvement, as well as the information presented in the consultation and their relation to recall.

Socio-emotional communication

Based on the assumption that older adults are more drawn towards emotion regulation than seeking information (e.g. Carstensen et al., 1999), there are two important reasons why socio-emotional communication may be particularly important for older cancer patients (Callahan et al., 2004). Firstly, older patients' need to 'be known and understood' by the clinician may prevail over their need to 'know and understand' their medical situation (Engel, 1988). Nevertheless, older patients are less likely to express their emotions (Butow, Brown, Cogar, Tattersall, & Dunn, 2002; Greene & Adelman, 1996; Gross et al., 1997) and clinicians may be less responsive to the psychosocial issues raised by older compared to younger patients (Adelman, Greene, Charon, & Friedmann, 1992). Secondly, socio-emotional communication may provide older cancer patients with a meaningful context to the information presented, thereby improving information processing and recall (Hanoch et al., 2007; Hess, 2005; Peters et al., 2006). In other words, detecting older cancer patients' emotions and tailoring communication accordingly may make the information more meaningful and enhance processing and recall of the information presented in the consultation.

Given the magnitude of emotions generated by a cancer diagnosis, one of the core functions of patient-clinician communication is responding to emotions (Epstein & Street, 2007). Several studies indicate that eliciting, acknowledging and empathizing with emotional expressions of patients have positive effects on their functioning and quality of life (see Epstein & Street, 2007 for an overview). Furthermore, a study by Brown (2001) showed that when physicians addressed the concerns written down by cancer patients on a question prompt list (QP), patients' anxiety decreased and recall increased. On the other hand, some have argued that too much focus on emotions may diminish the amount of attention allocated to information giving (Roter, 2000; Schmid Mast, Kindlimann, & Langewitz, 2005) resulting in poorer recall. In Chapter 5, we will shed more light on this issue by exploring how older cancer patients' expressions of need for information or emotional support (i.e. 'cues' Zimmermann, Del Piccolo, & Finset, 2007) and the subsequent response of the clinician subsequent affect recall.

The presence of a companion

Family and friends play an important role in coping with serious illnesses such as cancer (Berg & Upchurch, 2007; Berg et al., 2008) and most cancer patients are accompanied to the consultation, often by their spouse or an adult child (Eggly et al., 2006; Giacalone et al., 2008). In a recent survey by Wolff et al. (2008) older patients reported that companions were commonly engaged in communication and information exchange (see also, Beisecker, 1994; Ellingson, 2002; Glasser, Prohaska, & Gravdal, 2001; Schilling et al., 2002; Street & Gordon, 2008). This study furthermore showed that accompanied patients were more satisfied with the communication and care provided by their physician. Studies of audio- or videotaped encounters reported that companions facilitate patient understanding by clarifying or expanding on information provided by the patient and/or clinician, asking questions and prompting patient involvement (Clayman, Roter, Wissow, & Bandeen-Roche, 2005; Ishikawa, Roter, Yamazaki, & Takayama, 2005). Put in terms of the SOC model, the presence of a companion may improve recall by compensating for losses in other domains.

Furthermore, companions help patients manage their treatment. Patients who receive support from others are more likely to follow treatment recommendations and more knowledgeable relatives are better prepared to help (DiMatteo, 2004). It follows that, ideally, not only the patient but also the companion should have sufficient recall of the information presented in a cancer consultation, especially as those who take care of older patients are more likely to be older themselves (Brown & Park, 2003). Companions may have a better recall of information as they are less likely to perceive the information as threatening and therefore better able to engage in deep information processing (Kruglanski et al., 2006). However, it is important to acknowledge that patients and companions may have different and even conflicting needs (Giacalone et al., 2006) and that older patients may participate less when they are accompanied (Greene, Majerovitz, Adelman, & Rizzo, 1994). In Chapter 6, recall of patients and companions will be compared and the influence of companion presence on patient recall will be explored.

Aims and outline of this thesis

Aims

The central aim of this thesis is to unravel the relationship between patient characteristics, communication between patient and clinician, and subsequent patient information recall in the context of medical consultations with older cancer patients. The ultimate goal is to reach an understanding of the ways in which the presentation of medical information can be improved so it is better remembered by older cancer patients. Based on the theoretical background presented above, we formulated a conceptual model of older patient-clinician communication and recall (see Figure 1.1), which guided the questions addressed in this thesis.

Outline

In the first part of this thesis we seek to shed light on how age influences communication between cancer patients and their clinician and the patients' subsequent recall of the content of the consultation, while at the same time looking at the importance of other age-related patient characteristics in this process.

Chapter 2 describes the results of a literature review exploring age differences in cancer patients' need for information and support surrounding their treatment for cancer (2, Figure 1.1). As the SOC model states, aging is associated with changes in goals. In addition, older people are increasingly likely to select goals related to emotional gratification at the expense of information and knowledge gathering. Furthermore, life circumstances and beliefs about cancer are likely to be different for cancer patients of different ages. We therefore expect to find age differences in the type and amount of information and support needs cancer patients have. In **Chapter 3** we a) assess to what extent age differences are present in older cancer patient-clinician communication (3a, Figure 1.1) and b) determine to what extent chronological age, other age-related patient characteristics (e.g. performance status, prognosis), and communication explain cancer patients' recall (3b, 3c and 3d, Figure 1.1). To achieve these aims, we employed secondary data analysis on data from a prospective study in which first encounters between cancer

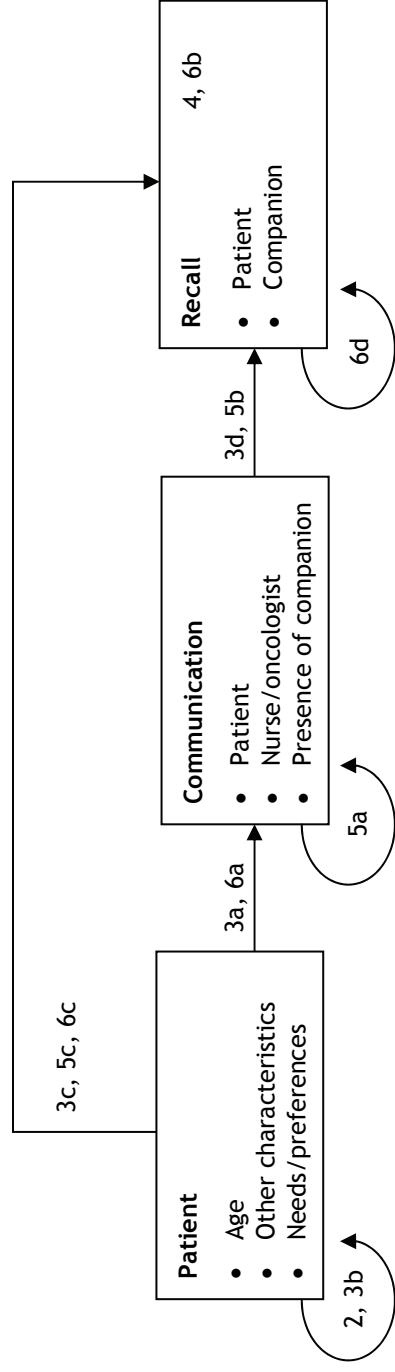
patients of all ages and their medical or radiation oncologist were audiotaped and data on participant's recall and background characteristics were collected. This study was carried out at two university hospitals in Australia at the outpatient departments of medical and radiation oncology. We expect to find age differences in communication and recall. However, we anticipate that other factors, such as having poorer health or a more severe disease, may interact with chronological age to influence recall over and above the effect of age. This study will be referred to as 'the Australian study'.

In the second part of this thesis, we focus solely on older cancer patients. We sought to examine whether two important aspects of communication influence older cancer patients' recall, specifically the clinician's responses to patients' expressions of emotions and needs for information (i.e. 'cues'); and the presence of a companion in the consultation. In terms of the SOC model, the emotional context of the consultation and the presence of a companion may compensate for age-related cognitive and physical decline and are therefore important to explore.

We conducted a prospective study in which we videotaped and analyzed nursing sessions with older cancer patients (aged 65 years or above) in preparation for chemotherapy treatment (**Chapter 4, 5, 6**). Video data were supplemented with questionnaires. Data collection took place in 10 hospitals spread out over The Netherlands between February 2005 and July 2008 at 14 outpatient departments of general internal medicine, oncology or lung-diseases. In these hospitals, older cancer patients were recruited in the short time frame between making the treatment decision together with the oncologist and their consultation with the nurse. A researcher travelled to the hospital to set-up an unmanned camera and read the questionnaires aloud to the patients, if necessary. This study was part of a larger study aimed at investigating the extent to which the communication during these nursing sessions is attuned to older cancer patients' needs and to improving treatment related education for older cancer patients. Box 1.1 depicts all measures used in this study; a more detailed description of the measures is given in the chapters concerned. Appendix A gives an overview of the overarching study and the accompanying intervention we developed. We will refer to this study as 'the Dutch study'.

Since this is the first study to investigate recall of information after nursing consultations in preparation of chemotherapy treatment, we could not find an existing questionnaire that suited our needs. In **Chapter 4**, we therefore developed a recall questionnaire (4, Figure 1.1). In **Chapter 5** we used sequence analysis to explore how nurses respond to older cancer patients' emotional and informational cues (5a, Figure 1.1) and how these responses influence recall (5b, Figure 1.1). We expect that if nurses endorse patients' cues, patients will remember more from the consultation. In **Chapter 6**, we a) explored patient and consultation characteristics associated with the presence of a companion in the consultation (6a, Figure 1.1), b) assessed and compared recall in older cancer patients and their companion (6b, Figure 1.1), and c) explored if patient and companion characteristics influence their own and one another's recall (6c and 6d, Figure 1.1). We expect that the presence of a companion may help the older cancer patient remember what is discussed in the consultation; either directly by improving patient recall or indirectly because 'two heads remember more than one'. In the final **Chapter 7**, We will review the findings from this thesis in the light of the conceptual model, discuss their implications for our understanding of the factors that influence communication between older cancer patients and their clinician and what these patients recall, and outline directions for practice and future research. Each of the following Chapters comprises a paper that is published or submitted and can be read on its own. Hence, the reader may experience some repetitions in methodology and theoretical background.

Figure 1.1 Conceptual model



Box 1.1 Overview of all measures

Measure	Australian study (Chapter 3)	Dutch study (Chapter 4, 5, 6)
Recall	Cued recall ¹ , telephone interview, open ended questions	Cued recall ¹ , written questionnaire, open ended questions, multiple-choice questions and completion items ²
Cognition		Beliefs about memory Telephone interview cognitive status
Health characteristics	Diagnosis Time since diagnosis Treatment goal Estimated prognosis Performance status	Diagnosis Time since diagnosis Treatment goal
Psychological characteristics	Anxiety	Anxiety
Background characteristics	Age, gender, level of education, living arrangements, children	Age, gender, level of education, living arrangements, children
Communication patient	<i>Audiotape observations:</i> Information needs and preferences Relative contribution to the conversation, question asking	<i>Videotape observations</i> Expression of information and emotional cues
Communication nurse/doctor	<i>Audiotape observations:</i> Type/amount of information provided	<i>Videotape observations:</i> Type/amount of information provided Type of responses to emotional and informational cues
Consultation characteristics	Duration	Duration Companion presence
Background characteristics companion		Age, gender, level of education, relationship with patient

¹*Cued recall means that participants were provided with one or more cues. They were, for example, asked to recall everything they could about the side effects of their regimen. The written questionnaire also provided cues.*

²*Because the multiple-choice and completion items added little insight beyond that provided by the open-ended scores, we do not discuss these recall scores in Chapter 5 and 6.*



2

Patient education about treatment
in cancer care: an overview of the
literature on older patients' needs

Abstract

Major issue. An increasing number of older people are treated for cancer. Several factors, such as co-morbidity and sensory deficits occur more frequently in older patients than in younger patients. In addition, their life circumstances, values and preferences may differ. These factors ask for tailored nurse-older patient communication. This paper reviews recent literature on the specific needs of older cancer patients in the treatment phase of the disease. **Findings.** No studies addressed treatment related needs of older patients specifically. The seventeen studies that controlled for age showed that many older patients want as much information about disease and treatment as possible, but they are less interested in details than younger patients. Furthermore, older patients reported less need for information about sexual consequences and psychosocial support. The results remain difficult to interpret because of variation in study designs and questionnaires. Moreover, none of the studies controlled for age related variables. **Conclusion.** Studies that illuminate the unique needs of older patients with cancer in the treatment phase of the disease are strikingly limited given the demographics of cancer in our society. Research is needed that explicitly investigates these needs and the influence of age-related changes in cognitive, physical and psychosocial functioning.

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Introduction

Cancer is primarily a disease of older people with approximately 60% of all cancer related deaths occurring in individuals aged 65 and over. As the world population is aging it is estimated that there will be an increasing number of older cancer patients in the years ahead (Yancik & Ries, 2004). Most of these patients receive treatment at some time during their disease. Although the older patient population is highly heterogeneous, a large number of them also suffer from physical and psychosocial conditions such as co-morbidity and cognitive decline that can influence (the side effects of) treatment (Balducci, 2003). A better understanding of age related needs of older individuals during communication about cancer treatment is critical for providing high quality care, and may prevent the risk of under-treatment in this highly vulnerable patient group (Greene & Adelman, 2003).

Patient education is important to prepare older cancer patients for the treatment and to help them to deal with side effects. In addition, the recent shift to outpatient and home-based treatment (Molassiotis, 2004; Young & Kerr, 2001) has increased the necessity of good patient education, as most patients and their caregivers now have to deal with treatment-related problems and side effects at home. This may be even more challenging if those who care for older patients at home are older themselves. In addition, providing cancer patients with tailored information has been found to improve their ability to cope with treatment, to reduce anxiety, increase satisfaction with treatment, and improve communication with family (see Hack et al. (2005), for an overview). Nurses have an important role in providing cancer patients with information and support regarding treatment (Galloway & Graydon, 1996). Tailored patient education, i.e. education which corresponds to patients' needs, values, wishes and psychosocial circumstances, is likely to be most effective (Epstein et al., 2005), as it increases the chance that the information is correctly understood, remembered and used by the patient (Petty, Wegener, & Fabrigar, 1997).

Needs can be conceptualized in a variety of ways. According to Hack et al. (2005), the communication needs of patients are inextricably linked to their communication goals, which are primarily related to optimal management of

the cancer (e.g. knowing what the side effects of treatment are) and optimal attention to the patient's psychosocial response to the experience of having cancer (e.g. discussing emotional functioning or daily activities). It is likely that needs will vary according to the age of a patient at the time of diagnosis and treatment. A 35-year-old mother of two with cancer will probably struggle with different problems than a widow aged 75. When the current cohort of older patients was younger, people rarely spoke about cancer openly, treatments were harsher and patients were often hospitalized to receive treatment. Although today's mortality rate for cancer has reduced and new methods of treatment have been developed, it is likely that many older individuals have maintained the early perceptions about cancer (Greene & Adelman, 2003). Green et al. furthermore argue that older patients may have different expectations of their own role and the role of the health care professional in the medical encounter. In addition to differences in attitudes, there is a greater possibility of the presence of cognitive impairment, loss of vision and/or hearing loss in older patients compared with younger patients that affects their ability to process and remember information (Fitch, Gray, & Franssen, 2001; Greene & Adelman, 2003). Also, older patients are likely to have lower education and make less use of the Internet. As a result, they may have more difficulties with medical jargon and are not as aware of the different types of cancers and new treatments as younger patients. On the other hand, studies suggest that older patients succeed better at coping with their disease compared to their younger counter parts (Chouliara, Kearney, Stott, Molassiotis, & Miller, 2004; Greene & Adelman, 2003) and are less insecure about for example their prognosis and treatment (Cassileth, Zupkis, Sutton-Smith, & March, 1980).

How do these factors influence the educational needs of older patients? A recent review by Rutten et al. (2005) showed that, in general, younger patients have a higher need for information than older patients. Older patients do, however, wish to know their diagnosis and to be kept informed about their treatment progress, but often do not wish to be told about progression of their illness and length of their survival (Chouliara et al., 2004). Studies also showed that older patients felt that they did not receive adequate assistance to cope with the side effects of treatment (Fitch et al., 2001) and experienced less contact, engagement and concern from doctors and nurses (Tishelman, 1993).

To our knowledge, no attempt has been made to provide an overview of the specific needs of older cancer patients in the treatment phase of their disease. The aim of this paper is to assess what aspects nurses have to consider when educating older patients about the treatment for cancer, by reviewing recent literature on this topic. More specifically, the following questions were asked:

1. How much information and support do older patients need during patient education about cancer treatment?
2. What kind of information and support do older patients need during patient education about cancer treatment?

Methods

Selection of studies

The present review focused on studies evaluating the needs of older cancer patients when they communicate with doctors and nurses about their treatment for cancer. Initial exploration revealed no relevant studies that were concerned exclusively with older patients needs. Therefore, the search was expanded to include patients of all ages and consecutively assessed the presence of age as a variable within these articles. Searches were conducted on Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, PsychLIT and CINAHL from January 1990 to April 2005, using the following search terms: patient, cancer, need, communication, patient education, information, professional-patient relations, and treatment or therapy. Both free text words and related MeSH terms were used.

Inclusion and exclusion criteria

Type of studies

Both qualitative and quantitative studies were included. Individual case reports and articles that reviewed the literature were excluded.

Type of participants

Studies had to involve patients diagnosed with cancer in consultation with doctors and nurses about any treatment for cancer in any clinical setting. Studies focusing on other clinicians (e.g. dentists) were excluded, as were

studies on complementary cancer treatments. Ideally, this review would have included studies with an a priori purpose of studying the needs of older cancer patients (i.e. 65 years or over) surrounding treatment. However, no studies of this type were found. Therefore, to avoid excluding potentially useful data, studies were included in which the relation between age and needs of patients was investigated, although not necessarily as a primary focus of the research.

Type of needs

Only studies on patients' need for information or support after the treatment decision had been made were included. To retain a specific focus, studies that only assessed patients' needs related to decision making about a treatment plan were excluded.

Table 2.1 Characteristics of studies included in the review (n=17 articles)[#]

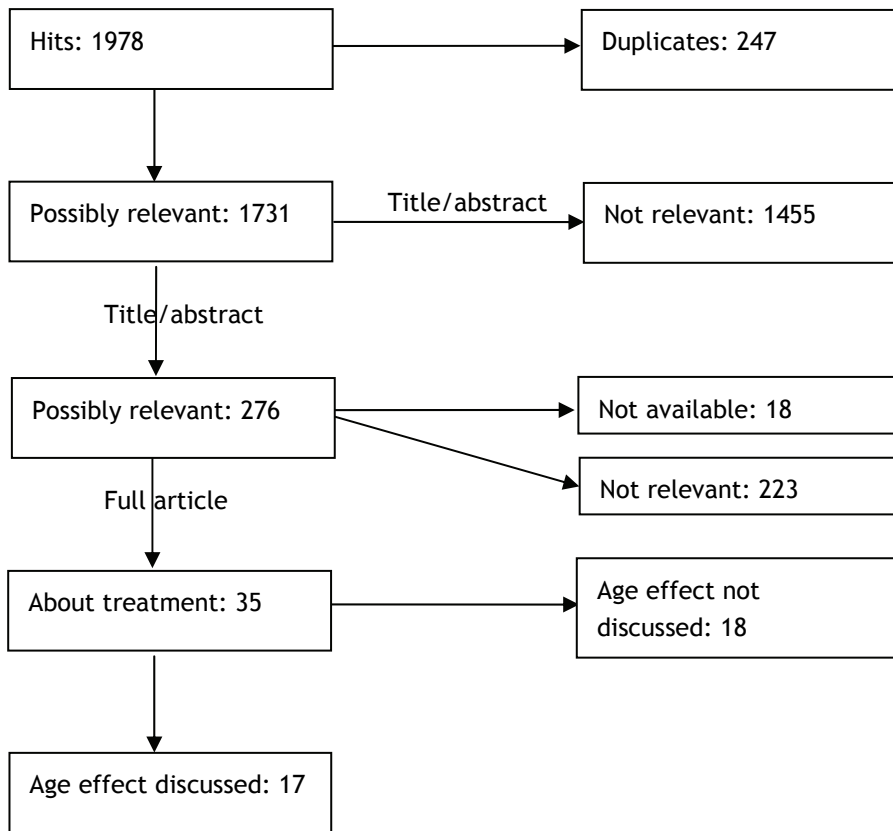
	N	%	References
Cancer phase			
During treatment	1	5.9	(25)
After treatment	5	29.4	(16;17;26;27;30)
Multiple stages	3	17.6	(18;20;31)
Various stages	8	47.0	(7;19;21-24;28;29)
Cancer site			
Breast	5	29.4	(7;19;20;22;23)
Gynaecological	3	17.6	(16;17;28)
Colorectal	1	5.9	(31)
Acute Myeloid Leukaemia	1	5.9	(18)
Prostate	2	11.8	(27;29)
Multiple sites	5	29.4	(21;24-26;30)
Treatment			
Surgery	1	5.9	(17)
Chemotherapy	3	17.6	(18;30;31)
Mixed treatments	8	47.0	(7;19;20;22;25-28)
Not specified	5	29.4	(16;21;23;24;29)
Treatment intent			
Adjuvant	1	5.9	(31)
Mixed (palliative and curative)	7	41.2	(21;24;25;27-30)
Not specified	9	52.9	(7;16-20;22;23;26)
Stage of disease/prognosis			
Mixed stages	10	58.8	(7;16;17;19;21-25;30)
Not specified	7	41.2	(18;20;26-29;31)

[#]The numbers in this Table correspond to the numbers with the references in Table 2.2

Inclusion procedure

A first selection for inclusion was performed by the first author (author1). Based on the titles and abstracts, all studies that clearly did not meet one of the inclusion criteria were excluded from the review. If there was any doubt about meeting the inclusion criteria, the full article was examined. A second selection was made by two reviewers independently (author1, author2). Based on the full articles, studies were checked against the criteria for inclusion. Disagreements regarding inclusion were resolved by discussion, if necessary a third reviewer (author3) was asked for advice. No relevant foreign (non-English) papers were identified.

Figure 2.1 Results of data extraction



Description of the results

The type and amount of information and support patients want may depend on the type of cancer, the extent of disease progression, the type of treatment they receive (Hack et al., 2005) and changes in the course of their cancer journey (Rutten et al., 2005). These and other characteristics of the studies were coded and summarized if the information was available (see Table 2.1). The most common features are described in the result section of this article. The two research questions guided the organization of the review findings. Studies are summarized under the categories preferences for amount of information and preferences for type of information. The latter category was, guided by the results, divided in psychosocial needs and needs related to sexuality and physical attractiveness. Under each subcategory, results related to needs for information are discussed first, followed by studies on needs for support. Studies that addressed more than one of the topics of interest were listed under each relevant category, along with the results specific to that category.

Results

The initial search of the literature resulted in a total of 1978 hits. Of these, 247 duplicates were identified and eliminated, leaving 1731 papers for further consideration. Reviews of these articles determined that 1455 studies were not relevant to the topic of this review but were more broadly related to cancer including biological aspects of cancer and clinical issues related to treatment, and general communication issues. The remaining 276 articles appeared relevant to the focus on older patients' needs concerning communication about cancer therapy. Detailed examination of these showed that 17 papers met all the inclusion criteria. The other 259 studies were excluded for one or more of the following reasons (in order of most frequent reason for exclusion): (1) studies that did not focus on cancer patients' needs related to treatment, (2) studies that did not discuss the older patients' needs, (3) studies evaluating the professionals' needs rather than the patients' needs, (4) studies that reviewed the literature or studies limited to describing an individual case, (5) studies focusing on clinicians other than doctors or nurses, (6) studies focusing on the needs of individuals with no cancer history, (7) studies focusing on

patients under 18 only, (8) age effect not discussed, (9) article not available. Figure 2.1 provides an overview of the inclusion process.

Study characteristics

Sample characteristics

Several studies utilized fairly heterogeneous patient samples regarding type of cancer, type of treatment and phase of the disease. Many of the studies examined the patients' needs in various, non-specific, phases of their illness (47%). About one third of the studies (29%) involved patients with a variety of cancer diagnoses and another third (29%) focused exclusively on breast cancer patients. The prognosis of the patients in the different studies varied (59%) or was not specified (41%). Many studies focused on a variety of treatments, including surgery, chemotherapy or a combination of these (47%) or did not specify the type of treatment involved (29%). In more than half of the studies, treatment intent (e.g. curative or palliative) was not mentioned (53%). Most studies were conducted either in the UK (41%) or in Canada (35%) (see Tables 2.1 and 2.2).

Study method

The majority of articles reviewed used a quantitative data collection approach solely (77 %). Commonly used survey instruments included instruments based on the ones originally developed by Cassileth et al. (1980; 29%), the Toronto Information Needs Questionnaire (TINQ-BC; Galloway & Graydon, 1996; 12%) and the Supportive Care Needs Survey (SCNS) by Bonevski et al. (2000; 12%) (see Table 2.2). There was great variation in focus and number of items across instruments.

Older patients' needs for information and support

Of the studies that were included, 15 mentioned a relation between treatment related needs and age (Bourgeois & Lotocki, 1999; Corney, Everett, Howells, & Crowther, 1992; Friis, Elverdam, & Schmidt, 2003; Galloway & Graydon, 1996; Graydon et al., 1997; Jahraus, Sokolosky, Thurston, & Guo, 2002; Jenkins, Fallowfield, & Saul, 2001; Lindop & Cannon, 2001; Luker et al., 1995; Meredith et al., 1996; Muthu et al., 2004; Sanson-Fisher et al., 2000; Steginga et al., 2001; Stewart et al., 2000; Wong et al., 2000), and two mentioned the

absence of an age effect (Iconomou, Viha, Koutras, Vagenakis, & Kalofonos, 2002; Knowles, Tierney, Jodrell, & Cull, 1999).

Amount of information

Five studies specifically addressed age differences in relation to the amount of information about treatment that patients prefer to receive and reported mixed findings (see Table 2). Jenkins et al. (2001) found in a heterogeneous sample of 2331 cancer patients that, compared to younger patients, relatively more older patients (>70) preferred to leave disclosure of details up to the doctor. They note, however, that a large proportion of patients over 70 years of age did want as much information as possible (81%). Similarly, Galloway & Graydon (1996) and Graydon et al. (1997) reported that younger women with breast cancer demonstrated greater need for information than older women. In the one qualitative study that mentioned age differences related to preferred amount of information, 21 acute myeloid leukemia (AML) patients were interviewed. The results showed that older patients especially, age not specified, were rarely interested in further medical information on their disease apart from basic information such as the duration of the treatment (Friis et al., 2003). A study by Muthu et al. (2004) showed that cultural background might play a role. They explored the patients' needs during a course of radiotherapy or chemotherapy and found that 65.5% of Asian patients older than 60 years wanted as much information as possible, compared to 91.3% of white British patients of the same age.

Two studies failed to show a relation between amount of information and age (Iconomou et al., 2002; Knowles et al., 1999). Knowles et al. (1999) examined the information needs of patients throughout their chemotherapy treatment period and found no significant relations between information needs either pre-, during and post treatment and age. The majority of patients reported that they would want information, irrespective of age. Similar results are reported by Iconomou et al. (2002), who assessed the overall and specific needs of patients during chemotherapy treatment.

To sum up, the majority of these studies show that most older patients prefer to receive less information about treatment than younger patients (Friis et al., 2003; Galloway & Graydon, 1996; Graydon et al., 1997; Jenkins et al., 2001).

However, in two studies no relation between needs and age was found (Iconomou et al., 2002; Knowles et al., 1999). Furthermore, the needs of older patients may vary according to their cultural background (Muthu et al., 2004).

Type of information

Treatment-specific information

Six studies showed that older and younger patients may need different types of information when discussing their treatment for cancer (Jahraus et al., 2002; Jenkins et al., 2001; Meredith et al., 1996; Sanson-Fisher et al., 2000; Stewart et al., 2000; Wong et al., 2000). Wong et al. (2000) examined the information needs of men with prostate cancer during treatment or at follow-up and found that patients wanting information on treatment-related issues were younger than 70 (and generally more optimistic). Stewart et al. (2000) explored the information needs of women with ovarian cancer in different stages of their disease and found that women aged 60 or over (who reported to be more in control) were more likely to need information only about the physical aspects of their health. In addition, the older women that were less depressed preferred to be told “the best possible outcome of the disease”. A couple of studies also reported more specific age related differences in the type of information patients want about treatment. For example, Jenkins et al. (2001) found that, compared to older patients, significantly more patients younger than 70 absolutely needed or would have liked information about: 1) the week by week progress, 2) all possible treatments, 3) all possible side effects of treatment, 4) how the treatment works. Similarly, Jahrhaus et al. (2002) reported that, compared with subjects aged 20-45 and aged 46-55, proportionally more so-called older patients (aged 56 and older) with primary breast cancer undergoing radiation therapy responded that they would “like to have” rather than “absolutely needed” information about: 1) all possible side-effects, 2) what the treatment would accomplish, 3) exactly what treatment would do, what the week-to-week progress is, 4) examples of cases in which treatment was effective and not effective. In addition to the previous results, a study on the information needs of recently diagnosed cancer patients showed that younger patients (aged <65) were more likely to want information about all possible treatments than older patients (aged 65-74) (24). Sanson-Fisher et al. (2000) showed that younger cancer patients (aged 31-60) consistently

displayed higher levels of need to be informed about “the things you can do to help yourself get well” than older patients (aged 71-90).

To summarize, compared to younger patients older patients reported less often that they needed information about treatment (Sanson-Fisher et al., 2000; Wong et al., 2000) and they more likely wanted to be told “the best outcome of the disease” and receive information on the physical effects of the disease only (Stewart et al., 2000). More specifically, information about: the week by week progress (Jahraus et al., 2002; Jenkins et al., 2001), all possible treatments (Jenkins et al., 2001; Meredith et al., 1996), all possible side effects of treatment (Jahraus et al., 2002), what the treatment would exactly do and accomplish (Jahraus et al., 2002; Jenkins et al., 2001) and things you can do to help yourself get well (Sanson-Fisher et al., 2000) seem to be relatively less important for older patients.

Sexuality and body image

Three studies reporting age differences in needs related to treatment effects on sexuality and body image (Bourgeois & Lotocki, 1999; Corney et al., 1992; Luker et al., 1995) were included in the review. Bourgeois-Law et al. (1999) investigated the information needs of patients with gynaecological cancer. They found that 50% of the women over 50 would have liked more information on sexuality and cancer compared to 67.6% of those under 50. Older women were also less likely to prefer a pamphlet as a format for receiving information about sexuality and cancer (treatment). Corney et al. (1992) found that younger women who had undergone major gynaecological surgery for cancer would have liked information on the effects of the operation on sexual function. They particularly would have liked their spouse to have received more information on sexuality (30% of the women in their 40s vs. 8% of the women aged over 50). Similarly, the younger breast cancer patients (<40 years and 40-60) in the study by Luker et al. (1995) rated information pertaining to sexual attractiveness as more important than did women in the 60+ age group. However, in this study the need for information about sexuality of the women was low, regardless of age. Apparently, older patients with gynaecological cancer have less prominent needs for information about cancer treatment and sexuality than younger patients.

Three studies reported age differences related to needs for support in dealing with treatment effects on sexuality (Lindop & Cannon, 2001; Sanson-Fisher et al., 2000; Steginga et al., 2001). In the study by Sanson-Fisher et al. (2000) cancer patients aged 31-60 years displayed higher need for help in the sexuality domain than those aged 70 years or older. Steginga et al. (2001) measured the supportive care needs of men with prostate cancer between 1 month and 5 years after diagnosis, during treatment or after treatment. In their study, younger men reported greater need in the sexuality domain. The mean age of patients in this sample was 68 (range 48-85). Lindop et al. (2001) identified support needs of women with breast cancer at various points of the illness. The younger age groups in their study (20-45 and especially the 46-53 group) expressed significantly higher needs than the 54+ group. Of particular importance to the middle-aged group was the concept of body image and femininity, these women in this age group expressed a stronger need to adjust to their changed appearance and to have this accepted by their husband/partner.

To summarize, older patients report less need for information about the effects of treatment and cancer on sexuality and body image either for themselves (Bourgeois & Lotocki, 1999; Corney et al., 1992; Luker et al., 1995) or for their partners (Corney et al., 1992) than younger patients do. In addition, younger patients seem to need more help in dealing with the effects of the disease and treatment on sexuality (Lindop & Cannon, 2001; Sanson-Fisher et al., 2000; Steginga et al., 2001).

Psychosocial issues

Three studies reported that older and younger patients have different needs for information about psychosocial issues (Luker et al., 1995; Stewart et al., 2000; Wong et al., 2000). Stewart et al. (2000) found that women with ovarian cancer under 60 years (who were more depressed) were more likely to report a need for information about coping techniques than other patients. Older women who felt in control were more likely to need information about the physical aspects of their health only and not about the psychological aspects. On the contrary, Wong et al. (2000) found that prostate cancer patients aged 70 or over (who were less depressed) wanted more psychological information, whereas, in general, men whose moods were less positive wanted more

psychological information. In a study with newly diagnosed breast cancer patients, Luker et al. (1995) found that older women (60+) rated information pertaining to their social life as more important than did younger women.

Age differences in relation to the need for psychological support were reported in two studies (Sanson-Fisher et al., 2000; Wong et al., 2000). Wong et al. (2000) showed that younger men with mental health issues needed more support and help with coping than older patients, as correlations between mental health indices (such as anxiety, depression and optimism) and coping and support needs were the strongest for patients under 70. Similarly, Sanson-Fisher et al. (2000) found that age was negatively associated with higher levels of need for help, for example in dealing with fears of the cancer spreading and concerns about the worries of those close to them. Cancer patients aged 31-60 years consistently displayed higher levels of unmet psychosocial needs than patients aged 70 or over.

To sum up, the results on age differences and information needs pertaining to psychosocial issues are mixed. Compared to their younger counterparts, older men (who were less depressed) reported higher needs for psychosocial information (Wong et al., 2000), in addition older women expressed a higher need for information about their social life (Luker et al., 1995). One study showed that younger women (who were more depressed) reported higher needs for information about coping with psychosocial issues than older women (Stewart et al., 2000). The relations between age and need for psychosocial support were more uniform. Younger patients displayed greater need for support and help in dealing with the disease than older patients (Sanson-Fisher et al., 2000; Wong et al., 2000). The question remains which role general mental health plays.

Table 2.2 Aims and results of studies included in the review (n=17 articles)

Reference	N	Age of sample	Design and method	Aim study	Age difference	Amount of info	Type of info
Bourgeois-Law et al., 1999 (Canada) ¹⁶	73	Range: 25-82 <50 (50.7%) >50 (49.3%)	Design: retrospective Method: newly developed questionnaire (quantitative)	Determine what information patients had received regarding the effects of cancer and its treatment on sexuality, what information they would have liked, and when, and in what format, they would have preferred to receive it.	Yes	-	Older patients: < need for information on sexuality
Friis et al., 2003 (Denmark) ¹⁸	21	<50 (n=9) 50-70 (n=6) >70 (n=6)	Design: cross-sectional Method: semi structured interviews (qualitative)	Describe the information needs from the patient's perspective and their information seeking behaviour.	Yes	Older patients: < need for information	-
Graydon et al., 1997 (Canada) ¹⁹	70	Average 49.7 Range 21-91	Design: cross-sectional Method: TINQ-BC (7) (quantitative)	Assess the information needs of women with breast cancer being treated by surgery, chemotherapy, or radiation therapy.	Yes	Older patients: < need for information	

Table 2.2 Continued

Reference	N	Age of sample	Design and method	Aim study	Age difference	Amount of info	Type of info
Iconomou et al., 2002 (Greece) ³⁰	100	Average 59.7 Range 20-80	Design: retrospective Method: newly developed questionnaire (quantitative)	Assess the overall preference for information and to identify specific information needs of Greek cancer patients receiving chemotherapy. And to delineate the profile of patients who knew the true diagnosis and to examine whether awareness had any effects on levels of satisfaction, emotional distress and global quality of life.	No	No significant effects of age were found	No significant effects of age were found
Jahraus et al., 2002 (Canada) ²⁰	79	20-45 (n=23) 46-55 (n=28) ≥56 (n=28)	Design: retrospective Method: questionnaire based on Cassileth et al. (12) (quantitative)	Evaluate the impact of an education program on the perceived adequacy of knowledge of patients with breast cancer receiving radiation therapy. Second, investigate patient's preferences regarding involvement in decision-making, amount and type of information wanted and preferred information seeking activities.	Yes	-	Older patients: < need for information on: all possible side effects effect treatment how treatment works week by week progress examples treatment effectiveness

Table 2.2 Continued

Reference	N	Age of sample	Design and method	Aim study	Age difference	Amount of info	Type of info
Jenkins et al., 2001 (UK) ²¹	2331	≤ 30 (4.8%) 31-50 (24.9%) 51-70 (46.4%) >70 (18.9%) Unknown (5%)	Design: retrospective Method: questionnaire based on Cassileth et al. (12) (quantitative)	Collect patients' information preferences using an adaptation of Cassileth's information Needs Questionnaire.	Yes	Older patients: < details	Older patients: < need for information about week by week progress all possible treatments how treatment works
Knowles et al., 1999 (UK) ³¹	80	Main sample: Average 62 Range 40-83 Sub sample: Average 59 Range 40-72	Design: prospective/longitudinal Method: newly developed questionnaire, partially based on Cassileth et al. (12) and semi-structured interviews (quantitative and qualitative)	Examine the existing knowledge and information needs of patients newly referred to an oncology clinic for consideration of adjuvant chemotherapy following surgical resection for colorectal cancer. 40 of these patients went on to be receive treatment and were assessed at four time points throughout their 6 months of chemotherapy.	No	No significant effects of age were found	No significant effects of age were found

Table 2.2 *Continued*

Reference	N	Age of sample	Design and method	Aim study	Age difference	Amount of info	Type of info
Lindop et al., 2001 (UK) ²²	12+489	20-45 (n=57) 46-53 (n=112) 54+ (n=318)	Design: retrospective Method: newly developed questionnaire based on semi-structured interviews (quantitative and qualitative)	Identify the self-assessed support needs of women with breast cancer at various points of illness and, establish if these needs formed clusters which could provide the basis for developing a standardized scale of needs for use by breast care teams in the evaluation of care.	Yes	-	Older patients: < need for support with issues related to body image and femininity
Luker et al., 1995 (UK) ²³	150	<40 (n=11) 40-60 (n=88) >60 (n=51)	Design: retrospective Method: Card Sorting Technique (23) (quantitative)	Establish the priority information needs of a sample of women newly diagnosed with breast cancer, and assess if information need was influenced by variables such as age, level of education and social class.	Yes	-	Older patients: < need for information about sexual attractiveness > need for information about issues related to their social life
Meredith et al., 1996 (UK) ²⁴	250	15-64 (56%) 65-74 (44%)	Design: concurrent Method: questionnaire based on Cassileth et al. (12) (quantitative)	Assess the needs of patients for information about their condition.	Yes	-	Older patients: < need for information about all possible treatments

Table 2.2 Continued

Reference	N	Age of sample	Design and method	Aim study	Age difference	Amount of info	Type of info
Muthu et al., 2004 (UK) ²⁵	82 Asian 220 White	Median 20 Range 18-77	Design: concurrent Method: questionnaire based on Cassileth et al. (12) (quantitative)	Find the information needs of British Asian cancer patients, and the extent of family involvement when the patient was given the cancer diagnosis and the patient's views about information disclosure.	Yes	A small minority wanted very little information, particularly patients older than 60 years and non-English speaking.	
Sanson-Fisher et al., 2000 (Australia) ²⁶	888	18-30 (2%) 31-40 (6%) 41-50 (16%) 51-60 (21%) 61-70 (27%) 71-85 (29%)	Design: cross-sectional Method: The Supportive Care Needs Survey (SCNS15) (quantitative)	Measure the prevalence of unmet needs among people receiving surgery, chemotherapy, or radiation therapy for cancer Examine the patients socio-demographic, disease and treatment variables predictive of the prevalence of different types of needs.	Yes	-	Older patients: < need for support with: the health system information sexuality psychosocial issues

Table 2.2 *Continued*

Reference	N	Age of sample	Design and method	Aim study	Age difference	Amount of info	Type of info
Steginga et al., 2001 (Australia) ²⁷	206	Average 68 Range 48-85	Design: retrospective Method: SCNS (15), adaptation (quantitative)	Assess the supportive care needs of men with prostate cancer who are members of prostate cancer self-help groups.	Yes	-	Older patients: < need for support and information about sexuality Older patients: < need for information about coping other than about physical aspects of health Preference to be told the "best possible outcome"
Stewart et al., 2000 (Canada) ²⁸	105	Average 55.8 Range 21-87	Design: retrospective Method: newly developed questionnaire (quantitative)	Assess the information preferences of women with ovarian cancer, their preferred role in decision-making and the influence of sociodemographic, disease related and psychological factors.	Yes	-	
Wong et al., 2003 (Canada) ²⁹	101	Average 70 <70 (n=39) ≥70 (n=62)	Design: cross-sectional Method: newly developed questionnaire (quantitative)	Determine the influence of psychological factors on how much and what type of information patients want and how much they want to participate in decision making with regard to their disease.	Yes	-	Older patients: > need for information on treatment psychosocial issues < need for support with coping

Discussion

The results from the studies that were included in this review suggest a small but marked difference between the amount and type of information older and younger patients want concerning treatment for cancer. In general, a large percentage of both older and younger patients want as much information as possible, but some studies showed that younger patients have a higher need for information than older patients. In addition, results seem to indicate that older patients prefer to receive information about the most important aspects of the disease and treatment but are relatively less interested in more detailed information. Compared to younger patients, older patients reported less often that they needed information about treatment and they were more likely to want to be told “the best outcome of the disease”. Older patients were also less likely than younger patients to report a need for information about: how the treatment works and what it accomplishes, what the week by week progress is, what all the possible treatments are, what all the possible side effects of the treatment are and things you can do to help yourself get well. The slightly higher information needs in younger people may be a reflection of a generational effect whereby younger people expect to be better informed and to be active participants in making decisions about their health care than people who are older (Galloway & Graydon, 1996). Jenkins et al. (2001) suggested that negative stereotypes of the elderly are common among health care professionals. If clinicians assume that there is an increase in passivity and helplessness in the elderly patient, then it is more likely that these negative aspects will prevail in the consultation. This leads to a doctor-centred rather than a patient-centered interaction, with the doctor in control of information giving. Although some older people may want the doctor to make decisions about management, they still require information about the reasons for decisions affecting their care (Jenkins et al., 2001). Alternatively, the personal and social responsibilities of younger people might increase their need for information (Galloway & Graydon, 1996).

In the literature reviewed, the need for information about the effects of treatment and cancer on sexuality and body image and the need for help and support with these effects of treatment seems to be higher in younger compared to older patients, irrespective of sex. This does not necessarily

mean that treatment does not have an effect on older patients. In a study assessing the information needs of patients with gynaecological cancer, Bourgeois-Law et al. (1999) found that older women were as likely as younger women to say that cancer and treatments had affected their sexuality. It must, however, be noted that the relative need for sexuality topics was low in general, regardless of age (Luker et al., 1995). Older patients may have already adapted to age-related changes in sexual function, hence the reduced need for information and support on this topic (Harden et al., 2002). In addition, widowhood is more likely to figure in the lives of older people, which may help to explain why being informed about sexuality issues was shown to be less important to older patients (Lindop & Cannon, 2001).

This review shows that younger patients appear to need more support in coping with the disease and treatment than older patients do. These results support previous findings that indicate that older patients succeed better at coping with their disease compared to their younger counterparts (Fitch et al., 2001; Greene & Adelman, 2003) and are less insecure about for example their prognosis and treatment (Cassileth et al., 1980). Nevertheless, in two studies, older patients reported higher needs for psychosocial information. These results seem to be influenced by patients' gender and general mental health and clearly more research is needed to gain knowledge about older patients' emotional and psychological needs.

There are several methodological issues that preclude drawing any strong conclusions. Since no specific articles on older patients' needs were discovered, the current review included studies in which the relation between age and needs in cancer treatment was investigated, although they were not necessarily a primary focus of the research. Consequently, most of the studies did not control for age-related variables that are expected to influence the needs of older patients, such as level of education and cognitive function. In addition, a limitation of many of the studies was that they predominantly used cross-sectional and retrospective designs. As needs of cancer patients change during the different stages of the disease (Hack et al., 2005) looking back at a previous treatment stage may elicit a coloured viewpoint. Furthermore, the instruments used are all developed from a different perspective and often contain items and domains with similar names that are conceptually and operationally quite different. As a consequence, there is great variation in

domains and number of items across instruments in the articles under review. Also, the type and amount of information and support patients need depends on the type of cancer, the extent of disease progression and the type of treatment they receive (Hack et al., 2005). Since we included only a few studies, all with patients with different diagnoses and treatments, it is difficult to look at the effects of the abovementioned factors. Additionally, the age categories in the different studies were far from uniform. In some studies patients were considered “old” when they were older than 50, whereas in other studies “older” patients were aged 70 or over. It is obvious that these differences may have influenced the results.

Effective patient education is known to be the key to outcomes in terms of more patient satisfaction, recall and understanding of information, less anxiety and mood disturbances and, ultimately, improved patient health status (Ong, Haes, Hoos, & Lammes, 1995; M. A. Stewart, 1995). Good communication with older patients requires knowledge of older peoples’ experiences with cancer and their needs. Nurses should stimulate patients, especially older ones, and give them the opportunity to ask questions. They should also be attentive to the individualistic nature of each older patient’s unique needs. An important first step may be to ask patients themselves what they need.

To conclude, this review has shown that even though age is taken into account in some studies, few studies have focused particularly on the needs of older patients concerning cancer treatment. In view of the rapid growing elderly population this is a rather surprising but not uncommon phenomenon. Older patients are underrepresented in cancer clinical trials (Lewis et al., 2003). Similarly, behavioural research has focused largely on younger adults whilst excluding older patients. Research is needed that explicitly investigates the needs of older cancer patients and the influence of age-related changes in cognitive, physical and psychosocial functioning on these needs. These age-related changes show differences within the elderly population between the young-old (65-75 yrs) and the old-old (>75 yrs) (Harden et al., 2002) and should be taken into account in further studies. Both qualitative and quantitative research should be carried out in order to explore more fully the needs of older cancer patients through the cancer journey.

A large, light gray, stylized number '3' serves as a background for the page. It is composed of several curved segments separated by thin white lines. A smaller, solid black number '3' is positioned at the top right of the larger '3', partially overlapping it.

3

Does age really matter? Recall of information presented to newly referred patients with cancer

Abstract

Purpose. To examine age- and age-related differences in recall of information provided during oncology consultations. **Patients and methods.** Two hundred sixty patients diagnosed with heterogeneous cancers, seeing a medical or radiation oncologist for the first time, participated in the study. Patients completed questionnaires assessing information needs and anxiety. Recall of information provided was measured using a structured telephone interview in which patients were prompted to remember details physicians gave about diagnosis, prognosis, and treatment. Recall was checked against the actual communication in audio-recordings of the consultations. **Results.** Recall decreased significantly with age, but only when total amount of information presented was taken into account. This indicates that if more information is discussed, older patients have more trouble remembering the information than younger ones. In addition, recall was selectively influenced by prognosis. First, patients with a poorer prognosis recalled less. Next, the more information was provided about prognosis, the less information patients recalled, regardless of their actual prognosis. **Conclusion.** Recall is not simply a function of patient age. Age only predicts recall when controlling for amount of information presented. Both prognosis and information about prognosis are better predictors of recall than age. These results provide important insights into intervention strategies to improve information recall in cancer patients.

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Introduction

During oncology consultations, patients are confronted with detailed information about their disease and treatment (Eggly, Penner, Albrecht et al., 2006) that is often difficult to understand and remember (Dunn, Steginga, Rose, Scott, & Allison, 2004; Ley, 1979). Previous studies have shown that patients forget substantial amounts of the provided information (Bakker et al., 1999; Dunn et al., 2004; Dunn et al., 1993; Jansen et al., 2008). Due to age-related cognitive changes, recall may be even more taxing for older patients which is likely to affect medical compliance and outcomes (Brown & Park, 2003).

Cancer is largely a disease of older age; more than one half of all new cases and almost two thirds of the deaths from cancer in the US occur among the 13% of the population that is aged 65 years and older (hereinafter referred to as "older" patients) (SEER Cancer Statistics Review, 1975-2004). Aging has been associated with decreases in speed of information processing (Salthouse, 1996) and working memory performance (Bopp & Verhaeghen, 2005; Grady & Craik, 2000). In addition, age-related conditions like sensory deficits (Baltes & Lindenberger, 1997; Valentijn et al., 2005) and health problems (Hess, 2005) reduce memory function.

On the other hand, older people's substantial knowledge and experience may weaken the impact of reductions in cognitive resources (Brown & Park, 2003; Hess, 2005). Besides, older people are better able to regulate their emotions (Mather & Carstensen, 2005) which might also compensate for negative age effects on cognition and information recall (Kessels, 2003). Moreover, there is a growing body of literature that has demonstrated the importance of variables other than chronological age such as functional-, psychological- and physical status in determining which patients do well and which patients do poorly in oncology settings (Balducci, 2007; Extermann & Hurria, 2007; Repetto & Balducci, 2002; Rodin & Mohile, 2007). Similarly, these variables may impair patients' recall, over and above the effects of age.

Literature on medical information processing in healthy adults nonetheless indicates that older adults have more difficulties remembering and following

physicians' instructions (Brown & Park, 2003). Studies conducted in clinical settings show mixed results (Butow, Brindle, McConnell, Boakes, & Tattersall, 1998; Gattellari, Butow, Tattersall, Dunn, & MacLeod, 1999; Lavelle-Jones, Byrne, Rice, & Cuschieri, 1993; Logan, Schwab, Salomone, & Watson, 1996; Pesudovs, Luscombe, & Coster, 2006; Rost, Roter, Bertakis, & Quill, 1990; Rushford et al., 2007). Variance of several study characteristics may have contributed to these discrepancies. For example, age differences in recall might be influenced by age differences in patient-physician communication. It is known that information that is tailored to patients' needs is better remembered (Morrow et al., 2005). Patients who actively participate in consultations are better able to direct the information flow (Brown, Butow, Dunn, & Tattersall, 2001), and consequently, they may also recall more. This is especially relevant as studies indicate that older patients participate less in consultations and ask fewer questions (Eggle, Penner, Greene et al., 2006; Siminoff, Graham, & Gordon, 2006) although others report that participation is not related to age (Street, Gordon, Ward, Krupat, & Kravitz, 2005; Street & Millay, 2001). Finally, there are small age differences in the type and amount of information cancer patients' value (Chouliara, Kearney, Stott, Molassiotis, & Miller, 2004; Jansen, van Weert, van Dulmen, Heeren, & Bensing, 2007). While the majority of older patients want as much information as possible about diagnosis and treatment, they often do not wish to be told all details about, for example, prognosis (Jansen et al., 2007).

It is essential to understand if and how age affects recall of information, because older cancer patients should have sufficient comprehension to make informed choices and correctly follow treatment regimens. Several studies have focussed on Comprehensive Geriatric Assessment (CGA), including investigations of cognition and the impact of cognitive dysfunction on care (Extermann & Hurria, 2007). However, little is known specifically about recall of information in older cancer patients.

To ensure good quality of care for the growing group of older cancer patients, effects of age have to be investigated while recognizing the heterogeneity of these patients (Balducci, 2007). In this study, we therefore explored if age is associated with recall of information presented to cancer patients while at the same time looking at the importance of age-related factors (e.g. anxiety,

ECOG performance status (Conill, Verger, & Salamero, 1990) and prognosis), information preferences and patients' active involvement in the consultation.

Patients and Methods

This study was part of a larger project investigating the effects on patients' question-asking triggered by a question prompt sheet (QPS) administered immediately before the first consultation with an oncologist in combination with active endorsement and systematic review of questions by the physician (Brown et al., 2001). Patients in the study were randomised to one of three conditions (passive physician + QPS; active physician + QPS; no QPS). The aim of the larger project was to determine if the question prompt sheet increased question-asking behaviour and to investigate the effect of increased question asking on psychological outcomes.

This project received ethics approval from the Central Sydney Area Health Service, Western Sydney Area Health Service and the University of Sydney Ethics Committees.

Participants

Consecutive patients with heterogeneous cancers, attending an initial consultation with one of five medical and four radiation oncologists at two university hospital outpatient clinics in Australia, were invited to participate. Exclusion criteria were; (i) age less than 18 years, (ii) non-English speaking, (iii) advanced incapacity, (iv) life-threatening illness other than cancer, and (v) non availability for follow up.

Procedure

Before the consultation, patients were informed of the study's purpose and requirements and permission was sought to audiotape the consultation. After providing written consent, participants completed two short questionnaires measuring anxiety and information needs and preferences.

Coding

Patient participation was measured by counting the number of questions (requesting information or guidance) asked during the consultation. Consultation length was timed as was the number of times the physician and patient spoke ('events'). We also calculated patients' relative contribution to the conversation (patient events / total patient and physician events).

A coding manual was developed with which two coders were trained. Coders re-coded a random 10% of their own consultations and 10% of the other's consultations to determine intra- and interrater reliability (Cohen's Kappa), which was 0.95 and 0.92, respectively.

Measures

Anxiety

Anxiety was measured using the 20-item Spielberger State Anxiety Scale (Spielberger, 1983). Respondents indicated their level of agreement (from 'strongly agree' to 'strongly disagree' on a 4-point Likert scale) to each of the items, with raw scores summed to produce a total score (20-80) and higher values representing higher levels of anxiety. This scale is used widely in cancer populations (Sheard & Maguire, 1999). Cronbach's alpha for this scale was .94.

Information needs and preferences

Participants indicated the amount of information they wanted about seven aspects of their disease using the Information Styles Questionnaire (Cassileth, Zupkis, Sutton-Smith, & March, 1980) rated on a 5-point Likert scale ('absolutely want no more' to 'want a great deal more'). Item scores were summed to produce a measure of information needs (7-35). Cronbach's alpha for this scale was .90. Information preference was assessed using two items derived from the same questionnaire. Questions addressed preferred amount of information (3-point Likert scale) and detail (5-point Likert scale). Because of the highly skewed distribution, scores on the *information* question were dichotomized into 'prefer all information' (score 3) and 'do not prefer all information' (scores 1 & 2). Likewise, scores on the *detail* question were dichotomized into 'prefer as many details as possible' (score 5) and 'do not prefer as many details as possible' (score 1-4).

Recall

Recall was measured using a structured telephone interview with open-ended questions (Dunn et al., 1993) within ten days after the consultation. Patients were prompted to remember details physicians gave about diagnosis (e.g. cancer site, extent), prognosis (e.g. chances of cure, life expectancy), and treatment (e.g. type of regimen, side effects). Each item recalled by the patient during the telephone interview was recorded and compared with the items mentioned by the oncologist during the audio taped consultation. The number and percentage of facts recalled accurately in total and for each category separately were calculated. To standardize recall in relation to the amount of information discussed in the consultations, we used percentage recall as the outcome.

Medical details

Physicians provided medical details for each patient enrolled in the study, including, treatment intent (curative, adjuvant, or palliative), estimated prognosis (weeks to months, years, normal life expectancy) and ECOG performance status, which is an assessment of the disease progression and daily living abilities of a patient ranging from 0 (fully active) to 5 (dead) (Conill et al., 1990).

Statistical analysis

Chi-square tests and independent samples *t*-tests, as appropriate, were used to compare patients who filled out the recall questionnaire to those who did not, as well as to compare younger patients (<65 years) to older patients (≥65 years).

Multiple regression analysis was used to examine predictors of percentage recall. The following six sets of variables were entered as separate blocks; (i) background characteristics, (ii) age (continuous) and age-related variables, (iii) information needs, (iv) patient participating level, (v) consultation characteristics, (vi) interaction terms (i.e. age×variable). The analysis revealed a quadratic, rather than linear, relationship between percentage recall and the total amount of information presented. To account for this non-linearity, we used a second-order polynomial regressor (quadratic) for this

variable (Fox, 1997). Throughout, type of intervention and whether or not the patient had listened to an audiotape of the consultation prior to the recall test was controlled for. All continuous variables were mean centred. As information preferences were uniformly quite high without variability, these were not used as a variable in the above analyses. All analyses were conducted using SPSS (version 14.0; SPSS Inc, Chicago, Ill) and results were considered significant when $p < .05$.

Table 3.1 Patient and consultation characteristics¹

		< 65		65 and over	
		no of patients	% of group	no of patients	% of group
Patient characteristics					
Age, years***	Mean (range)	48.7 (18-64)		70.5 (65-83)	
	SD	10.6		4.4	
	No of patients	166		92	
Gender***	Female	87	52.4	26	28.3
	Male	79	47.6	66	71.7
Education*	Completed < ten years	38	23.2	30	33.7
	Completed High School	65	39.6	39	43.8
	Tertiary-non university or university	61	37.2	20	22.5
Diagnosis	Digestive/gastrointestinal	24	15.7	20	22.0
	Lung	5	3.3	5	5.5
	Genitourinary	23	15.0	21	23.1
	Breast	41	26.8	10	11.0
	Haematologic/blood	22	14.4	11	12.1
	Gynaecologic	6	3.9	3	3.3
	Skin	18	11.8	16	17.6
	Other	12	7.8	3	3.3
Treatment intent***	Curative	97	63.0	32	36.4
	Palliative	42	27.3	40	45.5
	Other	15	9.7	16	18.2

Table 3.1 *Continued*

		< 65		65 and over	
		no of patients	% of group	no of patients	% of group
Prognosis**	Weeks to months	39	25.7	39	44.3
	Years	88	57.9	43	48.9
	Normal life expectancy	25	16.4	6	6.8
ECOG performance status ^{2***}					
	0	117	75.5	48	53.3
	1	33	21.3	23	25.6
	2 or more	5	3.2	19	21.1
Anxiety pre-consultation ^{3**}					
	Mean (range)	43.1 (20-80)		38.5 (20-77)	
	SD	13.8		12.3	
	N	165		92	
Total information needs					
	Mean (range)	29.5 (9-35)		29.3 (10-35)	
	SD	5.4		6.1	
	N	164		92	
Preferred amount of detail					
	All details	136	82.4	78	84.8
	Not all details	29	17.6	14	15.2
Preferred amount of information					
	All information	149	90.3	83	90.2
	Not all information	16	9.7	9	9.8
Total no of questions asked*					
	Mean (range)	12.6 (0-53)		9.8 (0-50)	
	SD	9.6		9.0	
	N	161		89	
Patients relative contribution ⁴					
	Mean (range; 0-1)	.42 (.22-.53)		.40 (.07-.54)	
	SD	.05		.08	
	N	161		89	

Table 3.1 Continued

		< 65		65 and over	
		no of patients	% of group	no of patients	% of group
Consultation characteristics					
Intervention	Control	87	52.4	43	46.7
	Passive physician + QPS	46	27.7	24	26.1
	Proactive physician + QPS	33	19.9	25	27.2
Consultation length					
(min)*	Mean (range)	31.9 (7.8-70.0)		28.0 (9.8-72.6)	
	SD	12.6		12.8	
	N	161		89	
No times listened to tape**					
	0	58	39.5	15	18.3
	1	43	29.3	26	31.7
	2 or more	46	31.3	41	50.0

Abbreviations: SD, standard deviation; ECOG, Eastern Cooperative Oncology Group; QPS, Question Prompt Sheet

¹Not all figures add up to 260 patients, due to missing data

²A higher score indicates poorer performance status

³A higher score indicates greater anxiety

⁴Patient events / total patient and physician events

* $p < .05$

** $p < .01$

*** $p < .001$

Results

Patient characteristics

Three hundred and forty-nine patients were considered eligible for the larger study to which 318 consented (91%). Patients who refused participation most commonly reported feeling too anxious; others were not interested or reported feeling too ill. Of the 318 patients who participated in the larger study, 260 patients (82%) completed the recall interview and comprised the sub sample for this study. Patients without a recall interview were more likely to have received a QPS with an active physician (39.7% versus 22.3%), and less likely to

have received a QPS with a passive physician (15.5% versus 26.9%) or be in the control group (44.8% versus 50.8%, $\chi^2(2) = 8.42$, $p < .05$). No other demographic and disease differences between those with a recall interview and those without were found. Participant characteristics are shown in Table 3.1.

No age differences in information needs or preferences were found. Most patients wanted all information and details, regardless of age. Younger patients did ask more questions (mean=12.6, SD=9.6, range 0-53) than older patients (mean=9.8, SD=9.0, range 0-50; $p < .01$). However, no age difference was found in patients' relative contribution to the encounter.

Presentation and recall of information

Mean consultation length was significantly higher for younger patients (31.9 minutes, SD=13.8, range 7.8-70.0) than for older patients (28.0 minutes, SD=12.3, range 9.8-72.6, $p < .05$). No significant age differences regarding total amount of information presented and total percentage recall were found (see Table 3.2).

Predictors of information recall

The final regression model including all predictor variables (Table 3.3) was significant and accounted for 29% of the variance in recall ($p < .001$). Age ($\beta = -.165$, $p < .05$), prognosis (years: $\beta = -.245$, $p < .05$; weeks to months: $\beta = -.324$, $p < .01$), amount of information presented ($\beta = -.191$, $p < .05$; quadratic component: $\beta = .157$, $p < .05$) and consultation duration ($\beta = -.307$, $p < .01$) all significantly predicted recall.

Table 3.2 Information discussed, recalled facts and % recall according to age (< 65 n=166; ≥ 65 n=92)

Category*	Consultations ¹ (%)		No of items (M/(SD)) ²		No of items recalled (M/SD) ²		% recall (M/(SD)) ²	
	< 65	≥ 65	< 65	≥ 65	< 65	≥ 65	< 65	≥ 65
Total	100	100	13.4 (4.4)	12.4 (4.1)	6.5 (3.2)	5.7 (2.7)	49.5 (20.2)	48.4 (22.2)
Diagnosis	99.4	100	1.9 (1.1)*	1.6 (.8)	1.1 (.8)	1.0 (.7)	58.6 (37.1)	67.4 (38.6)
Treatment	98.8	100	6.4 (2.4)	6.4 (2.0)	3.3 (1.8)	3.2 (1.7)	53.5 (25.1)	51.9 (25.1)
Prognosis	91.0	83.7	2.3 (1.1)	2.2 (1.2)	.9 (.9)	.8 (.7)	42.4 (37.6)	38.7 (38.2)
Tests	68.7	66.3	1.5 (.7)	1.4 (.7)	.8 (.7)	.6 (.6)	52.4 (44.2)	45.8 (41.1)
Medical other	62.0	51.1	1.7 (1.1)	1.4 (.8)	.6 (.7)	.4 (.6)	36.9 (42.2)	30.7 (42.7)
Psychosocial	54.2	44.6	1.7(.8)*	1.4 (.5)	.5 (.6)*	.3 (.5)	31.2 (40.4)	22.0 (40.4)
Help available	13.9	18.5	1.0 (.0)	1.0 (.0)	.5 (.5)	.3 (.5)	52.2 (51.1)	29.4 (47.0)

¹ The percentage of consultations in which items were discussed, age differences tested using Chi Square statistics (discussed vs. not-discussed).

² Calculated over all consultations in which at least one item from the category was discussed

*p<.05

**p<.01

***p<.001

Contribution of variable blocks

There was no influence of the background variables gender and level of education on recall ($\Delta R^2 = .02$, n.s.) and this remained the same in all subsequent blocks.

The block with age-related variables was significant and accounted for 11% of the variance in recall ($p < .01$). Prognosis was a significant predictor, whilst chronological age, ECOG performance status, treatment intent and anxiety were not. Patients with an estimated prognosis of years ($\beta = -.302$, $p < .01$) or weeks to months ($\beta = -.463$, $p < .001$) had lower recall scores compared with patients with normal life expectancy (see also Table 3.4). Prognosis remained a significant predictor of recall in subsequent blocks. The next block, containing information needs, did not influence recall ($\Delta R^2 = .01$, n.s.), and this remained the case throughout. Adding the block with the participating behaviour variables did influence recall ($\Delta R^2 = .03$, $p < .05$). Number of patient questions significantly predicted recall ($\beta = -.198$, $p < .01$); the more questions patients asked, the less they recalled. Relative patient contribution did not influence recall; this remained the same in all subsequent blocks.

The final block containing consultation characteristics was significant and accounted for 10% of the variance in recall ($p < .001$). Total amount of information presented ($\beta = -.191$, $p < .05$; quadratic component: $\beta = .157$, $p < .05$) and consultation duration ($\beta = -.307$, $p < .01$) were both significant predictors of recall; recall was lower after longer consultations and when more information was presented. The positive quadratic component shows that the decrease in recall slows down when the highest amounts of information are presented. Furthermore, introducing these variables revealed a negative association between age and recall ($\beta = -.165$, $p < .05$). This indicates that recall did decrease with age but that this effect was suppressed by differences in consultation length and the amount of information presented in consultations with patients from different ages. Finally, the effect of number of patient questions disappeared ($\beta = -.002$, n.s.) when the block with consultation characteristics was introduced. None of the interactions between age and the other variables were significant.

Table 3.3 Multiple regression analysis of percentage accurate recall (n=203)^{1,2,3}

Blocks	% recall	
	B	SE
Intercept	55.075	4.755
Background variables		
Gender (female) ⁴	3.085	2.839
Education (year 10 or less) ⁴		
Completed High School	4.584	3.315
Tertiary-non university or university	-0.044	3.917
Age and age-related variables		
Age of patient	-0.249*	0.110
Prognosis (normal life expectancy) ⁴		
Years	-10.035*	4.157
Weeks to months	-14.224**	4.844
ECOG status (0) ^{4,5}		
1	3.773	3.434
2 or more	-3.179	4.975
Anxiety pre-consultation ⁶	-0.009	0.109
Information needs (total score)	0.081	0.248
Patient participating behaviour		
Number of questions asked	-0.004	0.172
Patients' relative contribution	-13.746	22.497
Consultation characteristics		
Total facts	-0.900*	0.371
Total facts quadratic, x ²	0.123*	0.052
Consultation length (minutes)	-0.488**	0.145
R ² final model		.29
Adjusted R ² final model		.22

¹The intervention and number of times listened to the tape were controlled for throughout

²The block with interaction terms is not included in this model

³All continuous variables were mean centred, thus the intercept can be interpreted as the average recall score of a (hypothetical) subject with scores of '0' for each predictor in the model

⁴Denotes dummy coded variable with reference group in brackets

⁵A higher score indicates poorer performance status

⁶A higher score indicates greater anxiety

*p<.05

**p<.01

***p<.001

Exploring type of information

As recall of information was negatively associated with prognosis, we tested the hypothesis that prognosis does not matter but rather, it is the emphasis that is put on prognosis in the consultation that does matter. Therefore, the amount of information presented about prognosis and the other information categories (diagnosis and treatment) were added to the final model, with separate regressions conducted for each category. The number of prognosis items presented significantly predicted recall ($\beta = -.214$ $p < .01$), explaining 3% of the variance in recall ($p < .01$). This suggests that the more prognosis information was presented, the less information patients recalled. Number of diagnosis and treatment items did not predict recall. This effect could not be explained in terms of levels of anxiety. Introducing the number of prognosis items discussed did not influence any of the other effects.

Table 3.4 Information discussed, recalled facts and % recall according to estimated prognosis (normal n=32; years n=132; weeks to months n=78)

Estimated prognose ²	No of items (M/(SD)) ¹			No of items recalled (M/SD) ¹			Recall (M/(SD)) ¹		
	normal	years	weeks to months	normal	years	weeks to months	normal	years	weeks to months
Total	12.8 (4.8)	12.8 (4.1)	13.5 (4.2)	7.4 [*] (3.4)	6.2 (3.0)	5.8 (2.9)	60.2 ^{***} (20.7)	49.4 (20.3)	43.1 (19.8)
Diagnosis	2.0 ^{**} (1.2)	2.0 (1.0)	1.5 (.7)	1.4 ^{**} (1.0)	1.1 (.8)	.9 (.7)	70.0 (32.5)	58.3 (36.8)	62.4 (42.1)
Treatment	6.3 (2.5)	6.3 (2.1)	6.9 (2.4)	3.7 (1.9)	3.3 (1.7)	3.0 (1.8)	63.0 ^{***} (26.0)	53.8 (23.5)	46.1 (24.7)
Prognosis	2.2 [*] (1.0)	2.2 (1.1)	2.6 (1.2)	1.2 (.9)	.8 (.8)	.9 (.9)	55.1 (38.1)	39.7 (39.2)	36.8 (33.6)

¹ Calculated over all consultations in which at least one item from the category was discussed

² Differences were tested using one-way ANOVA's

* p<.05

** p<.01

*** p<.001

Discussion

Our analysis revealed that younger and older patients correctly recalled 49.5 % and 48.4 % of the information, respectively. It is difficult to compare recall rates found in different studies, because of variance in study characteristics (e.g. recall assessment methods). Nevertheless, this resembles the results of other studies showing that, regardless of age, cancer patients forget substantial amounts of information (Bakker et al., 1999; Bruera, Pituskin, Calder, Neumann, & Hanson, 1999; Dunn et al., 1993; Jansen et al., 2008).

Age significantly decreased recall of information but this effect was only present when consultation length and total amount of information presented were taken into account. Apparently, if consultations are longer and if more information is presented, older patients have more trouble remembering information. Physicians seemed to have anticipated this effect by adjusting the amount of information they presented according to age. Also, older patients asked fewer questions than younger patients. And contrary to our expectations, the more questions patients asked, the less they recalled. However, this effect disappeared when controlling for consultation length and amount of information presented.

More importantly, our study revealed that estimated prognosis predicted recall. Patients with a poorer prognosis consistently remembered less information than patients with a better prognosis. Perhaps not surprisingly, these results indicate that recall is not simply a function of chronological age, but rather a more complicated outcome. This is supported by the fact that although the variables in our model explained a substantial amount of the variation in recall (29%), a larger part remained unexplained. Clearly, other factors, for instance cognition and frailty, have to be explored to completely understand the mechanisms underlying information recall.

It is unclear why and how patient prognosis predicts recall. Perhaps patients with a more advanced disease forget information to maintain a positive spirit (Hack, Degner, & Parker, 2005). Even though many patients want to be fully informed, more vulnerable patients, including patients with a poorer prognosis, seem less likely to want to know every detail of their disease and

treatment (de Haes, 2006). Confronting patients with information they do not want is often not effective, as they will not remember it (Back & Arnold, 2006a). Gattellari and colleagues (1999) found that denial plays a role in misunderstanding information provided by oncologists. Mechanisms of denial may act to block news perceived as threatening; similarly denial may be a mechanism to explain poorer recall in patients with a poorer prognosis as found in this study. Indeed, there is evidence that people with a repressive coping style remember less information than nonrepressors (Myers & Derakshan, 2004). A review on denial in cancer patients showed that denial is more frequent in older patients and in patients in a more progressing stage of their disease (Vos & de Haes, 2007). The relation between denial, prognosis and recall seems evident, but more research is needed to disentangle the mechanisms involved.

In general, patients do not hear much of what is said after bad news is delivered (Ptacek & Eberhardt, 1996). We therefore explored the hypothesis that it is not prognosis as such, but rather discussing prognosis that impedes patients' recall. Interestingly, the more prognosis information was provided, the less information patients recalled, regardless of their actual prognosis. Although it is not exactly clear how patients conceptualize 'bad news' (Hack et al., 2005), prognosis information may be associated with the risk of death and disease recurrence, inducing negative emotions (Leighl, Gattellari, Butow, Brown, & Tattersall, 2001). Other studies have found that negative emotions result in attentional narrowing (Easterbrook, 1959), perhaps explaining the effect of prognosis information on recall. Communicating prognosis requires careful tailoring to individual patient's preferences for more or less information and balancing the needs for clear information while maintaining hope (Butow, 2005; Hack et al., 2005). Recently, methods have been proposed to assist physicians with this clearly demanding task (Clayton et al., 2007).

Our study is limited by the fact that we did not measure patients' cognitive function (Neupert & McDonald-Miszczak, 2004). However, the similar results for recall in younger and older patients do not make it likely that cognitive disorders played an important role in this study. In addition, our definition of older patients (≥ 65) may be challenged. In future studies, it might therefore be worthwhile to include measures that detect older patients who are

especially vulnerable, for instance frailty assessments or geriatric screening tools (Balducci, 2007). Also, it is important to use prompts when measuring recall. Originally, we measured recall by simply asking patients what the physician had said (free recall). Since this resulted in very low recall scores, we had to prompt patients to remember information.

In this study, more than half of the provided information was forgotten. Older patients were particularly vulnerable to information overload. However, our results also clearly suggest that ‘the frail are not always the elderly’ (Apro, 2005) as a poorer prognosis seems to reduce recall of information independent of age. There is a substantial body of literature on how to improve recall. Suggestions are to tailor information to patients’ needs, (Morrow et al., 2005) prioritize to the most important, personally relevant information, (Kessels, 2003) organize and categorize (Ley, 1979), repeat (Morrow, Leirer, Carver, Tanke, & McNally, 1999; Yardley, Davis, & Sheldon, 2001) and summarize the most relevant information and review it on subsequent visits (Sahay, Gray, & Fitch, 2000), use simple language (Kessels, 2003) and provide written materials (Kessels, 2003) or audiorecordings (Hack, Pickles, Bultz, Ruether, & Degner, 2007; van der Meulen, Jansen, van Dulmen, Bensing, & van Weert, 2008) for later referral. More research is necessary regarding the complex interaction of wanting to know and not wanting to know (denial) and the influence of the emotional context.



4

Recall in older cancer patients:
measuring memory for medical
information

Abstract

Purpose. Remembering medical treatment information may be particularly taxing for older cancer patients, but to our knowledge this ability has never been assessed in this specific age group only. Our purpose in this study was to investigate older cancer patients' recall of information after patient education preceding chemotherapy. **Design and Methods.** We constructed a recall questionnaire consisting of multiple-choice questions, completion items, and open-ended questions related to information about treatment and recommendations on how to handle side effects. Immediately after a nursing consultation preceding chemotherapy treatment, 69 older patients ($M=71.8$ years, $SD=4.1$) completed the questionnaire. We checked recall against the actual communication in videorecordings of the consultations. **Results.** On average, 82.2 items were discussed during the consultations. The mean percentage of information recalled correctly was 23.2% for open-ended questions, 68.0% for completion items and 80.2% for multiple-choice questions. **Implications.** Older cancer patients are confronted with a lot of information. Recall of information strongly depended on question format; especially active reproduction appeared to be poor. To improve treatment outcomes, it is important that cancer patients are able to actively retrieve knowledge about how to prevent and recognize adverse side effects and that this is checked by the health professional. We make suggestions on how to make information more memorable for older cancer patients.

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Introduction

Older adults experience age-related cognitive changes that may impede their ability to process and remember information (Brown & Park, 2003; Kessels, 2003), as they often process information more slowly (Salthouse, 1996) and have reduced working memory capacity (Bopp & Verhaeghen, 2005; Grady & Craik, 2000). Memory for information in older adults can be hampered further in case of sensory deficits (Grady & Craik, 2000), fatigue, stress (Brown & Park, 2003), or depression (Paterniti, Verdier-Taillefer, Dufouil, & Alperovitch, 2002). Age-related losses are linked to the nature of the memory task. Decrements are usually slight in tasks relying on automatic processes, such as implicit memory tasks or recognition, but more substantial in tasks requiring effortful processing such as recall (Grady & Craik, 2000; Light, 1991). Unfortunately, when delivering information to older patients, health professionals rarely take notice of age-related cognitive changes and memory decline (Brown & Park, 2003).

Providing medical information to older patients by taking into account their cognitive functioning is likely to increase treatment compliance and informed decision-making (Kessels, 2003). Overviews of research on medical information processing by Brown and Park (2002, 2003) suggest that, relative to younger patients, older patients have greater difficulty in recalling several types of medical information, including the contents of drug labels, treatment recommendations, appointments, and familiar or unfamiliar disease information. However, these studies mainly examined age effects by using written medical information. Recall may be especially difficult for older patients in more complex processing environments, such as during patient education consultations, with large amounts of information discussed and little time to evaluate the information. In case of cancer, recall may be more problematic because the stigma and fear associated with the diagnosis, the complexity of the medical information, and the uncertainty regarding the course of the disease and treatment add an emotional dimension (Siminoff, Ravdin, Colabianchi, & Sturm, 2000).

Several studies have assessed recall of information in cancer patients and suggested that older cancer patients have more problems recalling medical

information compared with younger patients (Butow, Brindle, McConnell, Boakes, & Tattersall, 1998; Butow, Dunn, Tattersall, & Jones, 1995; Olver, Turrell, Olszewski, & Willson, 1995; Ong et al., 2000). However, the distinctive issues and concerns of the aging patient in relation to recall in particular have hardly been investigated. Therefore we need to focus more specifically on the recall process in this age group. As Sanderman, Coyne, and Ranchor (2006) rightfully pointed out, although the age of patients is always reported, age is much less discussed as a substantive concern. This is rather remarkable, because cancer disproportionately strikes individuals aged 65 years and older, and this group is growing (Yancik, 2005).

Better recall of information may enhance the chance that the older patient behaves adequately when treatment-related problems occur, and therefore this ability is worthwhile to assess. It has been suggested that, to measure recall comprehensively, the health professional should judge it against the information that was actually given (Michie, French, Allanson, Bobrow, & Marteau, 1997). Furthermore, the type of questions used should be determined by the goal of assessing recall (Martinez, 1999; Messick, 1995), which may either be directed at the reproduction or recognition of information. In addition, a recall questionnaire should be based on knowledge about information processing and memory in the older adult (Carlson, Feldman-Stewart, Tishelman, & Brundage, 2005). Literature suggests that performance on open-ended questions declines more with age than does performance on multiple-choice and completion items (Craik & McDowd, 1987). This suggests that older adults might not be able to actively recall all information but may still recognize it correctly (Brown & Park, 2003; Morrow et al., 2005).

In the present study we extend the knowledge about older patients' memory for medical information. First, we investigate older patients' memory for medical information in a real-life and complex setting, that is, education about chemotherapy treatment. Most studies on memory for medical information in older adults have taken place in a laboratory, without the numerous distracters and cues present in real-life situations. Second, chemotherapy is a relatively common treatment in older patients with cancer, and even "minor forgetting" can have serious health consequences for these patients. Nevertheless, to our knowledge, no studies to date have examined

the older cancer patient's memory for information about chemotherapy treatment, despite the fact that a disproportionate percentage of older adults have cancer. Third, question type is expected to influence quality of recall. We chose to use open-ended questions to measure recall for recommendations about side effects, because it is especially important that patients can actively reproduce recommendations to be able to recognize and diminish adverse side effects of treatment. We used multiple-choice and completion items to measure recall for medical-technical information (e.g., treatment name), because recognition memory is often sufficient for this type of information, as patients can easily look it up when necessary. Finally, we compare recall responses to the actual content of the consultations, providing a more ecological measurement of recall.

Methods

Participants

We recruited participants from consecutive new patients in 10 Dutch hospitals between February of 2005 and July of 2006. The Medical Ethical Committee of the University Medical Centre Utrecht, The Netherlands, granted permission for the study, supplemented by local feasibility statements from all participating hospitals.

To be eligible for the study, patients had to meet the following inclusion criteria: they had to (a) be aged 65 years or older, (b) be receiving chemotherapy for the first time or for the first time in 5 years, (c) not be participating in a Phase III clinical trial, (d) have sufficient command of the Dutch language, and (e) have no history of cognitive deficiencies according to the medical file. We recruited a sample of 114 patients. Of these, 83 patients (72.8%) gave informed consent for us to videotape the consultation, and 31 patients refused to participate: 16 felt it was too much, 6 did not want the consultation to be videotaped, 4 felt too sick, 4 refused without giving a reason, and 1 gave a reason that was unknown to us. Of the 83 participating patients, 71 (85.5%) completed the recall questionnaire, and 12 declined: 5 for practical reasons, 5 felt it was too much, 1 felt too sick or too tired, and 1 refused without giving a reason. We later excluded 2 patients, 1 because of

cognitive problems and another because he was assisted in completing the questionnaire, leaving 69 patients. Patient education was provided by 1 of 39 nurses, with an average of 1.8 times per nurse (range, 1-5).

Patient education about chemotherapy

Most oncology nurses in The Netherlands use a general guideline to inform patients who are scheduled to receive chemotherapy: *The Treatment Guide to Chemotherapy* (Moosdijk & Postma-Schuit, 2000). In our sample of 39 nurses, 2 nurses from one hospital did not use this guideline. Topics usually explained during a consultation of approximately 1 hour are routines involved in chemotherapy, possible side effects from the chemotherapy, and how to deal with these. In some hospitals, the nurses also take the patients' medical history.

Procedure

We sent eligible patients a letter prior to being educated about chemotherapy to inform them about the study, including the video recordings. One day before their visit, one of the researchers telephoned the patients to answer any existing questions they might have. Just before starting the consultation, we obtained written informed consent from both the patient and the nurse, after which a researcher started the video recording and left the room. The unmanned camera was positioned to show the nurse's full face; patients were seen from behind or the side. Immediately after the consultation, patients were asked to complete a questionnaire, including recall. A researcher was available to read the questions aloud to the patients, if necessary.

Measures

Observation of information and recommendations

We analyzed the videotapes by using an elaborate observation checklist developed for this study. We generated the checklist by using the *Treatment Guide to Chemotherapy* (Moosdijk & Postma-Schuit, 2000), relevant literature, pilot video observations, and information from previous studies on patient education (Tromp, van Dulmen, & van Weert, 2004; van Weert, van Dulmen, Bar, & Venus, 2003). We defined an information item as a segment of speech

expressing a single idea concerning treatment and disease-related issues (Dunn et al., 1993). The categories in the checklist covered two main domains: (a) *information* about treatment and related issues and (b) *recommendations* on coping with potential side effects. Information categories included general information, history taking, cancer-specific information, treatment details, information about hospital routines, and possible side effects. Recommendation categories included coping with side effects, side effects that should be reported immediately, hygiene, consequences for daily life, and psychosocial coping. Additional elements that were discussed, but not included in the standard checklist, could be added to each category of the checklist, resulting in a complete content analysis of the consultation.

Measurement of recall

We measured recall by using The Netherlands Patient Information Recall Questionnaire, which is a structured questionnaire comparable with that of Dunn and colleagues (1993). To ensure content relevance (Messick, 1995), the questionnaire aimed to include questions representative of the main topics discussed in the consultations and at the same time relevant for patients coping with chemotherapy treatment. We again generated questions by using pilot observations of videotaped consultations and items presented in the *Treatment Guide to Chemotherapy* (Moosdijk & Postma-Schuit, 2000). Content validity of the questionnaire was tested by experts and 10 patients aged 65 years and older who had just been educated about chemotherapy. On the basis of their input, we revised the items considered ambiguous or difficult to understand. We used a mixture of question formats, including multiple-choice questions, completion items, and open-ended questions. As a consequence, recall measures differed in complexity, ranging from recognition (multiple-choice questions) to active recall (open ended questions; see, e.g., Martinez, 1999).

Because this study involved older patients, we took special care to make the instructions and questions brief and simple. In addition, we printed the questionnaire in a large and easy to read font: Universe 12 (Sensis, Grave, The Netherlands). Because the content of education varied and the patients should not become worried by the suggestion that they had missed important information, all questions provided these additional response options: “not

discussed” and “discussed, but I can’t remember the details.” The questions covered the two main domains of the observation checklist: information about treatment and recommendations on coping with potential side effects.

Information about treatment

The first part of the questionnaire consisted of 13 questions on the details of chemotherapy treatment and side effects. Included were 7 completion items requiring a short response (e.g., “How many treatments will you receive?”) and 6 multiple-choice questions with four to six response options (e.g., “Will all patients experience the same side effects of chemotherapy treatment?” with these response options: “not discussed,” “discussed, but I can’t remember the details,” “side effects are the same for all patients that are treated with this specific chemotherapy treatment,” and “side effects can be different for each patient”).

Recommendations on coping with potential side effects

The second part of the questionnaire consisted of 11 open-ended questions. In 8 questions, patients were asked to write down recommendations on dealing with side effects. Each question began with the stem “Please write down as many recommendations as possible that the nurse gave about ...,” followed by one of the following eight categories: eating and drinking, mouth, fatigue, hair, skin, stools, hygiene, and reasons to alarm the doctor or a nurse. Patients were asked 3 additional questions starting with the stem “Did the nurse talk to you about ...,” followed by one of the following: “the consequences of chemotherapy treatment for your daily life (e.g., taking care for yourself at home or hobbies),” “feelings and emotions that you might experience as a result of chemotherapy treatment (e.g., anxiety, depressive feelings, or hope),” and “how you and the people around you can cope with the disease.” They were instructed to write down any recommendations that were discussed. We analyzed the latter two questions together, resulting in the subcategory of psychosocial issues.

Coding reliability

We trained two coders. We resolved discrepancies during training through discussion. The main coder observed all consultations. The other coder coded a random 20% (15 consultations) of the main coder’s consultations. Interrater

reliability (mean Cohen's kappa) for the content analysis of the videos averaged 0.79 (range, 0.50-1.0). Interrater reliability for coding recall averaged 0.78 (range, 0.38-1.0) for the multiple-choice questions and 0.77 (range, 0.48-1.0) for the completion items in the first part of the questionnaire and 0.96 (range, 0.87-1.0) for the open-ended questions in the second part. We could not calculate Cohen's kappa for two of the recall questions because one or two observers had no variation in their score. To summarize, interrater reliability for both the video observations and the recall questionnaire can be considered satisfactory (Dunn, 1989).

Background data

Sociodemographic characteristics

We measured background variables with questions about age, gender, education, marital status, children, living arrangements, and occupation.

Disease status

We gathered data on diagnosis, type and nature of chemotherapy treatment, and other medical information from the nurse or oncologist.

Statistical analysis

To determine differences between participants and nonresponders, we used chi-square and *t* tests where appropriate. We used descriptive statistics to summarize the frequency with which items were discussed and to assess the level of recall. We conducted the following analyses: first, we analyzed the occurrence of information and recommendation items in the consultations, as measured by an analysis of the content of the videotaped visits; second, using the content analysis as a reference, we determined the proportion of items recalled. We compared the recall for each patient, as measured in the questionnaire, with the actual information provided.

Information about treatment

We scored the patients' answers to the multiple-choice questions in a straightforward manner: We marked the written responses to each of the questions as either correct or incorrect (i.e., 0 or 1 points). Each response to a completion item received 0 (no correct information provided), 1 (some correct

information provided), or 2 (all correct information provided) points. There were two exceptions. For the completion item “Chemotherapy usually consists of several treatments. When is your first treatment?” a score between 0 and 3 could be obtained (for the correct date, day of the week, and time). For the completion item “In your own words, please write down five (5) side effects that the nurse mentioned that you might experience as a result of the chemotherapy treatment,” patients received between 0 and 5 points, depending on the number of correct side effects mentioned. We did not include in the analysis those questions concerning items that were not discussed. Subsequently, we calculated a proportion correct score for each patient by dividing the score on each question by the maximum score that could be obtained for that question and multiplying by 100. We calculated a total recall score for each patient by averaging the scores on all questions.

Recommendations on coping with potential side effects

A recall score could be determined for a category of recommendations if at least one item of that category was scored on the observation checklist. Recall scores could range from 0 (not recalled), to 1 (recalled partially), to 2 (recalled accurately) points. For each of the 11 categories of recommendations, we computed a total score for each participant by summing all the points earned within that category. We then converted this total into a percentage score (i.e., we divided it by the maximum number of points that could be obtained for that category and multiplied by 100). Finally, we established a total recall score, that is, the mean recall percentage per patient.

The number of missing values was limited, as the researcher was present in the room and checked if all questions were answered. If responses were still missing, we did not include the question itself in the analysis, but we did calculate the average score for the remaining questions. Three patients filled out only the second part of the recall questionnaire with open-ended questions. In addition, we excluded the completion item about side effects from analysis for four patients because they completed an older version of the questionnaire and we therefore could not reliably code this item. We performed all data analyses by using SPSS version 12.0 (Statistical Package for the Social Sciences, Chicago, IL).

Table 4.1 Demographic and disease characteristics of the sample (n=69)

Characteristic	No.	%
Gender		
Male	48	69.6
Female	21	30.4
Age		
M (SD)	71.8 (4.1)	
Range	65.3-85.0	
Educational level		
Low	32	46.4
Middle	15	21.7
High	22	31.9
Living arrangements		
Alone	12	17.4
With partner	47	68.1
With partner and child(ren)	5	7.2
With child(ren)	2	2.9
Other	2	2.9
Unknown	1	1.4
Primary tumor site		
Digestive-gastrointestinal	30	43.5
Lung	16	23.2
Genitourinary	9	13.0
Breast	6	8.7
Hematologic	4	5.8
Gynecologic	3	4.3
Unknown	1	1.4
Time since diagnosis		
0-1 months	15	21.7
1-2 months	17	24.6
2-6 months	21	30.4
6-12 months	1	1.4
1-5 years	6	8.7
>5 years	6	8.7
Unknown	3	4.3

Results

Patient characteristics

On average, patients were 71.8 years of age (SD=4.1) and the majority (75.7%) were seeing a nurse within 6 months of their first diagnosis of cancer (Table 4.1). Most patients were male (69.6%), lived together with their partner (68.1), had digestive or gastrointestinal (43.5%) cancer, and had a lower educational background (46.4%). Participating patients did not differ in age, gender, or diagnosis from non-participating patients.

Table 4.2 Information items provided

Category	Consultations (%)	No. of Items (M, (SD))	Range
Information Total	100.0	45.3 (9.4)	24-64
Introduction			
History taking	95.7	5.7 (3.7)	0-17
General information	98.6	3.1 (1.2)	0-5
Cancer specific information	79.7	1.6 (1.2)	0-4
Treatment			
Side effects	100.0	21.7 (5.8)	8-33
Blood and bone marrow	98.6	6.4 (2.9)	0-12
Digestive system	100.0	5.1 (1.5)	2-9
Skin and hair	98.6	4.6 (2.0)	0-9
Mouth	94.2	1.7 (1.1)	0-6
General wellbeing and fatigue	89.9	1.5 (.9)	0-4
General information	85.5	1.3 (.8)	0-3
Eyes and ears	29.0	0.7 (.8)	0-3
Sexuality	43.5	0.6 (.7)	0-3
Details of therapy	100.0	10.1 (2.5)	5-16
Hospital routines	92.8	3.1 (2.1)	0-8

Notes: Consultations (%) refers to the percentage of consultations in which elements were discussed. No. of items refers to the mean number of items discussed per consultation, averaged over all consultations (n=69).

Information and recommendations provided by nurses

The mean amount of information and recommendations presented in the 69 consultations was 82.2 items (range 33-127). On average, 45.3 of these items concerned general information about disease and treatment (Table 4.2) and 36.9 items were recommendations on dealing with side effects (Table 4.3).

Information about treatment

In all consultations, the nurses provided standard introductory information, for example about the goal of the consultation and the *Treatment Guide to Chemotherapy* (Moosdijk & Postma-Schuit, 2000). Side effects were discussed most extensively, especially side effects concerning blood and bone marrow. This was followed by treatment details, such as the treatment plan, how the treatment works, and logistical information. Routines in the hospital during treatment were discussed concisely (Table 4.2).

Table 4.3 Recommendations made

Category	Consultations (%)	No. of Items (M, (SD))	Range
Recommendations Total	100.0	36.9 (13.5)	7-69
Recommendations: side effects			
Digestive system	95.7	8.0 (3.9)	0-18
Eating, drinking and nausea	95.7	6.8 (3.4)	0-15
Stools	66.7	1.3 (1.3)	0-5
Hygiene	92.8	6.2 (3.2)	0-13
Mouth	95.7	4.7 (2.6)	0-14
Skin and hair	94.2	3.9 (2.5)	0-10
General well-being and fatigue	82.6	2.7 (1.8)	0-6
Blood and bone marrow	58.0	1.0 (1.1)	0-4
Sexuality	52.2	0.7 (0.9)	0-3
Eyes and ears	29.0	0.4 (0.7)	0-2
Recommendations: miscellaneous			
Side effects to report	100.0	8.1 (3.5)	1-14
Psychosocial issues	42.0	0.8 (1.2)	0-5
Daily life	24.6	0.3 (0.5)	0-2

Notes: Consultations (%) refers to the percentage of consultations in which elements were discussed. No. of items refers to the mean number of items discussed per consultation, averaged over all consultations (n=69).

Recommendations on coping with potential side effects

The nurses discussed reasons to alarm the doctor or a nurse most extensively. Recommendations on side effects were also discussed, in particular those related to the digestive system. The nurses talked relatively less often about dealing with sexuality and how to handle effects of chemotherapy on the eyes and ears. The influence of chemotherapy on daily life, such as housekeeping and hobbies, and psychosocial issues, such as experienced emotions and coping with the disease, were discussed least elaborately (Table 4.3).

Table 4.4 Patients' recall of information items

Category and Question Type	No. of Questions	No. of Patients	Max. Score (M)	Recall Score (M)	Recall Score (%)
Information Total					
Multiple choice	6	66	8.9 (1.7)	7.1 (2.2)	80.2 (19.4)
Completion item	7	65	13.6 (2.9)	9.2 (3.4)	68.0 (19.3)
Side effects					
Multiple choice	2	66	3.8 (0.7)	2.9 (1.3)	76.5 (31.9)
Completion Item	1	61	4.5 (.8)	3.2 (1.5)	71.0 (30.3)
Details of therapy					
Multiple choice	4	66	5.1 (1.4)	4.2 (1.6)	82.8 (21.3)
Completion Item	6	66	9.3 (2.4)	6.2 (2.5)	67.8 (20.8)

Notes: No. of Patients refers to the number of patients for whom a recall percentage could be calculated; Max. Score refers to the average maximum score to be obtained, averaged over all consultations in which at least one item from the category was discussed and for which patient recall could be calculated; Recall Score (M) refers to the mean number of items recalled per consultation, averaged over all consultations in which at least one item from the category was discussed and for which patient recall could be calculated; Recall Score (%) refers to the mean percentage calculated over all consultations in which at least one item from the category was discussed and for which patient recall could be calculated. Standard deviations are shown in parentheses.

Recall of information

Information about treatment

The first part of the questionnaire consisted of six multiple-choice questions and seven completion items, and we analyzed these types of questions separately (Table 4.4). When measured with multiple-choice questions, 76.5% of the information about side effects was recalled and 82.8% of the details

about chemotherapy was recalled (e.g., name of the treatment, duration of treatment, and how the treatment works). Using the completion items, these figures were 71.0% and 67.8%, respectively. Overall, recall scores were higher for the multiple-choice questions (80.2%) than for the completion items (68.0%). With multiple-choice questions, there is always a chance of guessing correctly. This chance depends on the number of response options. In this study, options varied between two and five. Using the Wilcoxon signed-rank test, we compared average scores on all six multiple-choice questions against the chance of guessing correct. On average, the number of correct scores appeared to be significantly greater than chance (from $T=300$, $p < .001$, to $T=21$, $p < .001$).

Table 4.5 Patients' recall of recommendations

Category	No. of Patients	No. of Items (M, (SD))	No. of Recalled Items (M, (SD))	Recall (% (SD))
Recommendations Total	69	34.7 (12.6)	7.5 (3.7)	23.2 (12.3)
Recommendations: side effects				
Skin and hair	65	4.2 (2.4)	1.2 (0.9)	36.1 (30.2)
Mouth	66	5.0 (2.5)	1.2 (1.0)	27.2 (24.6)
Digestive system	66	7.2 (3.5)	1.6 (1.3)	21.5 (16.7)
Stools	46	1.9 (1.1)	0.5 (.5)	31.4 (39.1)
Eating and drinking ¹	63	6.1 (2.8)	1.3 (1.2)	20.5 (19.6)
Hygiene	64	6.6 (2.9)	1.7 (1.0)	27.5 (21.0)
General well-being and fatigue	57	3.3 (1.5)	0.8 (0.7)	26.6 (31.1)
Recommendations: miscellaneous				
Psychosocial issues	29	1.9 (1.1)	0.5 (0.6)	27.4 (40.9)
Daily life	17	1.1 (0.3)	0.3 (0.5)	26.5 (43.7)
Side effects to report	69	8.1 (3.5)	1.3 (1.0)	20.4 (20.4)

Notes: No. of Patients refers to the number of consultations in which at least one item from the category was discussed; No. of Items refers to mean number of items discussed per consultation, averaged over consultations in which at least one item from the category was discussed; No. of Recalled Items refers to the mean number of items recalled averaged over consultations in which at least one item from the category was discussed; Recall (%) refers to the percentage calculated over all consultations in which at least one item from the category was discussed. Standard deviations are shown in parentheses

¹items related to nausea are excluded as nausea was not measured in the recall questionnaire.

Recommendations on coping with potential side effects

On average, patients accurately recalled 7.5 out of 34.7 recommendations (23.2%; see Table 4.5). Eighty percent of the recalled recommendations were recalled completely accurately, and the remainder were recalled only partially. In consequent analyses, we summed and averaged the completely and partially recalled items.

Recommendations on side effects relating to hair and skin were recalled best, with an average score of 36.1%. Reasons to alarm the doctor or a nurse reached the lowest recall score, 20.4 %. Of the recommendations on psychosocial issues, 27.4% were accurately recalled, as were 26.5 % of the recommendations on dealing with the consequences of chemotherapy for daily life. However, these items were only discussed in a limited number of consultations.

Discussion

In this study we document the information recalled by older cancer patients after a chemotherapy education session with a nurse. We used different types of questions (multiple-choice, completion, and open-ended items) and compared patients' answers with the actual communication during the encounters, as measured by an observation checklist.

Nurses discussed an average of 82.2 items in this study, of which 45.3 items related to information about details of chemotherapy treatment, hospital routines, and possible side effects. In addition, the nurses gave on average 36.9 recommendations on coping with side effects and related issues. We based the definition of information or recommendation items in this study on the research of Dunn and colleagues (1993). They found that, on average, 25.4 items were discussed in oncology consultations with an average duration of 28 minutes, one third taken up by physical examination. This translates to approximately 27 items in 20 minutes and corresponds to the 82.2 items discussed in 60 minutes in the current study, which provides a validation of our observation checklist.

In general, the older patients in this study had difficulty remembering items. The patients recalled only 23.2% of the recommendations given on handling side effects as measured with open-ended questions. The percentage of accurately recalled information about treatment was 80.2% for the multiple-choice questions and 68.0% for the completion items. We did not counterbalance the different question formats over the two categories, making it difficult for us to pinpoint why the multiple-choice questions and completion items were better remembered (as recall could be influenced by both the format and content of the questions). For example, some studies showed significantly lower recall of recommendations compared with other medical information (Ley, 1979). Also, our findings are in line with previous findings regarding question type and quality of recall. That is, several studies in cancer patients used one question format to measure recall across different content areas, related to both medical-technical information and recommendations, and found similar results. High recall percentages ranging from 68% (Dunn, Steginga, Rose, Scott, & Allison, 2004) to 80% (Bakker et al., 1999; Bruera, Pituskin, Calder, Neumann, & Hanson, 1999) were reported in studies using multiple-choice questions, whereas more than five times lower recall percentages were obtained with open-ended questions (Dunn et al., 1993). This suggests that the method of measurement accounts for at least part of the differences in recall scores that we found in our study.

In support of this suggestion, the different types of questions are known to require different levels of cognitive processing. Both multiple-choice questions and completion items do not require elaborate cognitive processing but rather tap from recognition memory (Martinez, 1999; Messick, 1995). In contrast, open-ended questions have a range of possible answers, requiring more complex information processing and active retrieval (Martinez; Messick). Cognitive aging theories suggest that the decrease in cognition that takes place with aging primarily occurs in effortful but not automatic processing (Brown & Park, 2003). Therefore, differences in recall scores for multiple-choice items and other formats might be even larger for older patients than for younger ones.

Some limitations of the current study should be noted. Because we did not assess the participants' preconsultation knowledge, we cannot draw

conclusions about the extent to which prior education contributed to subsequent knowledge. We tried to reduce this bias by looking at the first nursing encounter with patients that had not been treated previously with chemotherapy or at least not in the preceding 5 years, the latter rarely being the case. In addition, we obtained the data after a single presentation of the chemotherapy treatment information, and it is possible that recall might have been higher after prolonged and repeated contact with the nurse. However, some studies have shown a decrease in the recall of information over time (McGuire, 1996; Ong et al., 2000). In the current study we measured recall at one time point, that is, immediately following the consultation, to prevent contamination of information gained after consultations. The patients need to remember the information longer, because in most cases treatment starts days after the nursing education session. It would therefore be interesting to investigate how much information is retained over time. Furthermore, in this study, 39 different nurses, with on average fewer than two consultations per nurse, delivered the education. Inconsistencies and variability may exist in the quality of delivery of the medical education across nurses because of the communication style of each nurse, and it might be argued that encounters of the same nurse are more similar than those of different nurses (Hox, 1995). However, the number of consultations per nurse was too small for us to investigate multilevel effects on information provision and recall.

Apart from the format and content of the questions, other factors might be related to older cancer patients' recall of information. We used a post hoc analysis to investigate two of these factors. First of all, we investigated if accurate recall was related to the amount of time spent on a topic by coding duration of topics for a subset of 30 consultations and comparing this with recall performance by the use of Pearson's correlation coefficient. We found no relation between the average time used to discuss information and recommendations and recall for these two categories ($r=-.052$, $p=.80$ and $r=.139$, $p=.48$, respectively). Second, we investigated the effect of perceived importance on recall of information. Do nurses emphasize certain content as important because they find it relevant for the patient? We tested this possibility by looking at how often nurses repeated the information in a subset of 20 consultations. In one third of these consultations, no information was repeated. In the remaining consultations, an average of 3.5 (range 1-8) items

was repeated, which is 4.3% of the average of 82.2 items discussed. This is in line with our observation that nurses provided patients with a large amount of information and do not seem to prioritize or signal important information by spending more time on the most important items or by repeating those items. At the same time, recall may be enhanced for information that is of particular relevance to the patient. Personally relevant information is processed more deeply (e.g., receives increased attention), leading to better comprehension, memory storage, and use of the information (Craik & Lockhart 1972; Ingram 1984). When measuring recall, researchers should therefore take into account the importance assigned to the information by both patients and nurses. A study is currently underway to investigate this issue. Finally, addressing patients' psychosocial and emotional needs is an important component of effective communication in health care settings (Liang et al., 2002). The quality of the nurses' socio-emotional communication strategies could impact patient receptivity to information, which in turn may influence recall and should be investigated further.

Although the claims that can be made on the basis of the current results are somewhat limited, it is possible to provide additional suggestions to make information more memorable for older cancer patients. First, it is critical to distinguish information that patients have to be able to *reproduce* with little help from information that patients can look up. It is known that health professionals often overestimate how effective they are in imparting accurate information to patients and this might therefore require further improvement (Ford, Fallowfield, & Lewis, 1994), for example, by checking older patients' active recall for important information. As we mentioned previously, patients in this study were confronted with a large amount of information. It is difficult to imagine that anyone can retain that much information accurately, especially as the patients in this study were experiencing a stressful time and cancer patients often report that stress limits their ability to remember what they have been told during consultations (Friis, Elverdam, & Schmidt, 2003; Harden et al., 2002). To improve understanding and recall, health care professionals should try to categorize information, be explicit, prioritize, summarize the most important points and leave less important information for other occasions.

Another key factor is language level; statements in simple language will be recalled better than will complex formulations (Kessels, 2003). Health care professionals should therefore avoid using jargon that is common to them but not to older patients. Furthermore, in this study we assessed recall immediately after the consultation. However, providing information does not mean that it remains accessible over time (McGuire, 1996; Ong et al., 2000). It might therefore be helpful to repeat important information (Morrow, Leirer, Carver, Tanke, & McNally, 1999) and review it with patients on subsequent visits. In addition, the fact that the patients in this study scored significantly greater than chance on the multiple-choice questions suggests that older cancer patients do recognize the information when they see it. So, remembering can be aided further by providing written materials (see Kessels, 2003) for later referral, as was done in the current study, and helping patients to access important information throughout their course of treatment. Finally, older patients could be encouraged to bring family members or friends with them to the consultation; literature suggests that a supportive accompanying individual may enhance communication (Liang et al. 2002), helping patients remember information and deal with treatment-related problems and side effects at home.

In conclusion, recall of medical information in older patients has so far been investigated mostly for written material and in laboratory settings. We conducted this study in a more complex and naturalistic processing environment, that is, education about chemotherapy treatment, and it revealed that older cancer patients are confronted with a lot of detailed information and recommendations. We observed a lack of retention for information about treatment that was passively recognized, but this was especially marked for recommendations that had to be actively generated. To facilitate meaningful comparisons among studies, it therefore seems important to consider and report precisely the measurement type used. Furthermore, to improve medical education for older patients, additional ecologically valid studies are needed that examine recall and more specifically variables that affect recall in complex, real-life settings.



5

Emotional and informational
patient cues: the impact of
nurses' responses on recall

Abstract

Objective. The current study investigates older cancer patients' informational and emotional cues and how nurses respond to these cues. In addition, the study evaluates these responses in relation to patients' recall of the information discussed in the consultation. **Methods.** 105 cancer patients (aged ≥ 65 years) completed a recall questionnaire after an educational session preceding chemotherapy treatment. Recall was checked against the actual communication in video recordings of the consultations. Independent observers used an adaptation of the Medical Interview Aural Rating Scale (MIARS) to rate the patients' emotional and informational cues and subsequent responses by the nurse. **Results.** Patients gave more informational than emotional cues. The most frequent response to patients' emotional cues was distancing followed by acknowledgement. Nurses gave appropriate information in response to the majority of informational cues. Patients' expression of emotional or informational cues did not influence recall and neither did nurses' responses to informational cues. Responses to emotional cues did show an effect. The more nurses' responded by giving 'minimal' encouragements (e.g. 'Hmmm'), the more patients recalled. On the other hand, distancing responses (e.g. ignoring the cue) were associated with lower recall scores. **Conclusions.** This study suggests that responding to patients' emotions impacts information recall. **Practice implications.** This study highlights the importance of addressing patients' expressions of emotions in the context of patient education, as it enhances the chance that information is recalled.

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Introduction

Having cancer is a very distressing experience for most patients (Butow, Brown, Cogar, Tattersall, & Dunn, 2002; Fallowfield & Jenkins, 1999; Jacobsen & Jim, 2008). Patients not only have to cope with the diagnosis of a life threatening illness, they are faced with invasive treatments and tests and have to make difficult decisions. Not surprisingly, most cancer patients report high needs for information and emotional support (Hack, Degner, & Parker, 2005; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). It is an important task for health providers to address the patient's emotions while concurrently giving information that the patient will understand and remember (Epstein & Street, 2007). However, it is unclear how health providers' responses to patients' emotions influence cognitive outcomes of the consultation, such as recall.

Despite their high needs for information and support, cancer patients are often hesitant to express these needs directly and for example ask questions. Patients are more likely to disclose their concerns indirectly, by what is often labelled 'cues' rather than clearly verbalizing them (Dimoska et al., 2008) (Butow et al., 2002; Zimmermann, Del Piccolo, & Finset, 2007). Cues are important to address as they may provide insight into the perspective of the patient and his or her feelings. According to a recent literature review by Zimmermann and colleagues (2007) that mainly focused on emotional cues, responses such as clarifying the cue, empathy, showing agreement (e.g. 'Right', 'Go on'), acknowledgement of feelings, are generally considered adequate. On the other hand, postponing, interrupting and avoiding cues or discouraging further disclosure are deemed less adequate responses.

Patients are an expert of their own physical and psychological state (De Valck, Bensing, Bruynooghe, & Batenburg, 2001) and adequate responses to cues may encourage patients to disclose their perspectives on illness and treatment (Mauksch, Dugdale, Dodson, & Epstein, 2008; Uitterhoeve et al., 2007). This may in turn reduce the patients' feelings of distress, increase the chance that the patient's agenda is voiced and that the information in the consultation is attuned to their needs (Mauksch et al., 2008; Neumann et al., 2007). Reduced distress and increased personal relevance of information have both been associated with increased information recall (Petty, Goldman, & Cacioppo,

1981; Pickersgill & Owen, 1992; Rimer & Kreuter, 2006), and the way health providers respond to patients' cues might thus influence recall.

Responding to cues may be even more important when communicating with older cancer patients, as they are less likely to express themselves (Butow et al., 2002; Eggly et al., 2006; Greene & Adelman, 1996; Siminoff, Graham, & Gordon, 2006). Also, as people get older, they are increasingly likely to focus on information that is emotionally meaningful to them (Carstensen, Isaacowitz, & Charles, 1999). According to some authors, when put into an emotionally meaningful context, it is easier for older people to process and therefore recall information (Hanoch, Wood, & Rice, 2007; Hess, 2005). Too much focus on emotions may, however, displace time for information giving and negatively influence recall (Rost & Roter, 1987), and patients may actually get more distressed (Eide et al., 2004).

In cancer care, nurses play an important role in providing patients with information about their disease and treatment. In this paper we focus on one specific aspect, i.e. education about chemotherapy treatment (Schofield et al., 2008; Verity, Wiseman, Ream, Teasdale, & Richardson, 2008). To optimally prepare patients for their treatment, information giving as well as responding to patients' emotional needs are major tasks for the nurse and patients and professionals have reported that the emotional dimension of nursing communication may especially require some improvement (Caris-Verhallen, Timmermans, & van Dulmen, 2004; Uitterhoeve, Duijnhouwer, Ambaum, & van Achterberg, 2003). The purpose of this study was twofold:

1. To describe nurses' cue responding behaviour in educational sessions with older cancer patients in preparation for chemotherapy treatment
2. To explore the effect of patients' emotional and informational cues and nurses' responses on patients' recall of information

We used sequence analysis rather than the traditional correlation analysis to allow a better understanding of what response followed a cue. Based on the literature as outlined above, we expected patient recall of information to be greater when nurses pick up and adequately respond to cues. More specifically, we expected that responses to emotional cues that facilitate

patients to express their concerns will increase recall whereas inhibiting patient disclosure will reduce recall. For informational cues, we expected that giving appropriate information and exploring cues will improve recall, whereas distancing responses and inappropriate information will reduce recall.

Methods

Participants

Participants were recruited from consecutive new patients in 10 Dutch hospitals between February 2005 and April 2008. The Medical Ethical Committee of the University Medical Centre Utrecht, the Netherlands, granted permission for the study supplemented by local feasibility statements from all participating hospitals. To be eligible for the study, patients had to meet the following inclusion criteria: (a) aged 65 years or older, (b) receiving chemotherapy for the first time or for the first time in 5 years, (c) not participating in a Phase III clinical trial, (d) sufficient command of the Dutch language, and (e) no history of cognitive deficiencies according to the medical file.

This study was part of a larger study investigating the effects of a communication skills training for oncology nurses on patient outcomes. After a pre-test, hospitals that participated in the study were randomized to receive the training. As part of this training, nurses practised addressing the emotional and informational needs of patients. In the present paper, patients from the experimental hospitals at post-test were excluded (n=44) as the training may have confounded the results.

Procedure

Eligible patients were sent a letter before the consultation to inform them of the study's purpose and requirements. Prior to the consultation, written informed consent was obtained from both patient and nurse, a researcher then started the video recording and left the room. The unmanned camera was positioned to show the nurse's full face, patients were seen from behind or the side. Immediately after the consultation, patients were asked to complete a

questionnaire, including information recall, background and disease characteristics as well as measurements of anxiety. A researcher was available to read the questions aloud to the patients, if necessary.

Measures

Video observations of cues and responses

The aim of this study was to describe nurses' responses to older cancer patients' emotional and informational cues and how this influences recall. A review of the literature (Caris-Verhallen et al., 2004) identified an observation instrument that best suited our aims, the Medical Interview Aural Rating Scale (MIARS; Heaven, Clegg, & Maguire, 2006; Heaven & Green, 2001). The MIARS is specifically developed for oncology settings and provides (amongst other things) the number of emotional cues expressed by a patient and a measure of nurse patient-centeredness by coding responses to each cue. As it does not cover informational cues, these were added to the instrument (see below). This instrument has been previously used to study cue-responding behaviours of oncology nurses (Heaven et al., 2006; Uitterhoeve et al., 2007). We used 'turns' as the unit of observation and analysis, meaning what the patient, companion or nurse says before the other takes over. A turn can therefore consist of several smaller elements or 'utterances'. Consultations were coded directly from the videotapes rather than using transcripts. That way, we could take non-verbal aspects (e.g. emotional tone of voice) into account when coding cues. The coding system was integrated in specialized software (The Observer, Noldus et al., 2000) and time and sequence indicators were automatically added during the coding procedure, resulting in sequential data. Nurses were unaware of the research question in our study.

Emotional cues and responses

Emotional cues were classified at three levels according to their level of intensity, i.e. hints of worry or concern, mention of worry or concern, clear expression of worry or concern. As cues are infrequent events, we collapsed these three levels together in all analyses to increase the power of the analyses (Zimmermann et al., 2007). The MIARS system distinguishes between three types of responses to emotional cues; exploration (by eliciting, clarification, or educated guess), acknowledgment (by an empathic statement, reflection or checking) and moving away or distancing (by blocking any further

disclosure, switching focus, or giving premature reassurance or inappropriate advice). Previous studies have shown that ‘minimal’ encouragers such as ‘back channel’ responses (‘Mmmmh’, ‘ah’), agreement (‘right’, ‘go on’) and functional silence may be important in relation to emotional cues (Eide, Quera, Graugaard, & Finset, 2004); therefore, we added this category to the original instrument. Responses were coded in the first turn after the patient cue (i.e. lag 1).

Informational cues and responses

Informational cues were defined as verbal information-seeking utterances, including direct questions (e.g., ‘Will I lose my hair?’) and indirect statements (e.g., ‘So it seems like you don’t think I will lose my hair?’). Responses to informational cues were coded as distancing and exploration responses, similar to the MIARS, and giving appropriate information and giving incomplete or inappropriate information. In line with Butow et al. (2002), responses to informational cues were coded as appropriate if they covered material of the same content as the cue and provided complete coverage of the issues raised by the patient. Informational cues and the subsequent responses by the nurse were incorporated in the MIARS protocol.

Coding reliability cues and responses

Previous studies have reported good interrater reliability of the MIARS (Heaven et al., 2006; Uitterhoeve et al., 2007). In the current study, all tapes were rated by one of three raters, all social scientists. Raters practised coding until uncertainties and questions were satisfactorily resolved. Interrater tests were completed on a randomly selected sample of 20 consultations. In line with Heaven et al., (2006), reliability was tested using intra-class correlation coefficients (ICC) using a two-way mixed effect model of consistency and single measure statistic. Reliability was coded for all responses, regardless of whether the coders agreed on the preceding cue. Based on Kappa statistics criteria (Altman, 1991), values between 0.21 and 0.40 are considered fair, values between 0.41 and 0.60 moderate and values > 0.61 good. We considered data to be reliable if the intra-class correlation was greater than 0.41. This might not be considered a very stringent criterion, but since the purpose of the study is exploratory, we deemed it acceptable. The ICC for coding emotional cues was 0.58 and 0.76 for coding informational cues. The

ICC for the responses to emotional cues ranged between 0.33 for distancing and 0.52 for acknowledgement (see Table 5.1). Responses to informational cues were coded with higher reliability, with ICCs ranging from 0.42 for distancing to 0.65 for appropriate responses.

Table 5.1 Patient cues and responses by the nurse (MIARS)[†]

Elements of the MIARS	Frequencies n (%)	Degree of agreement (ICC)
Patients cues		
Emotional cues	667 (68.6)	0.58
Informational cues	1457 (31.4)	0.76
Nurses' responses		
<i>On Emotional cues</i>		
Exploration	73 (9.9)	0.44
Acknowledgement	160 (29.5)	0.52
Distancing	275 (35.8)	0.33*
'Minimal' encouragement	156 (24.7)	0.51
<i>On Informational cues</i>		
Exploration	36 (2.8)	0.47
Appropriate information	942 (65.7)	0.65
Inappropriate information	336 (28.5)	0.48
Distancing	52 (3.1)	0.42

[†]*n*=105 for the cues calculated over all consultations, *n*=93 for the proportion responses to the emotional cues (12 patients did not express emotional cues), and *n*=103 for proportion responses to the informational cues (2 patients did not express informational cues)

* Because the ICC for this response is <0.41, we consider it to be unreliably coded

Video-observations of information discussed and recall

The videotapes were analysed using an observation checklist developed for this study that is extensively described elsewhere (Jansen et al., 2008b). An information item was defined as a segment of speech expressing a single idea concerning treatment and disease-related issues (Dunn et al., 1993). The categories in the checklist covered two main domains: (a) information about treatment and related issues (e.g. treatment details and cancer-specific information) and (b) recommendations on handling potential side effects (e.g.

diet and hygiene). Additional elements discussed, but not included in the standard checklist, could be added to each category of the checklist, resulting in complete content analysis of the consultation (i.e. total amount of information discussed). Interrater reliability (mean Cohen's Kappa) for the content analysis of the videotapes was 0.79.

Recall measurement

Recall was measured using a structured questionnaire, the 'Netherlands Patient Information Recall Questionnaire (NPIRQ)' that was developed in conjunction with the observation checklist (Jansen et al., 2008b). Items recalled in response to eleven open-ended questions about treatment recommendations were compared with items mentioned by the nurse during the videotaped consultation. The number (absolute) and percentage (proportional) of facts recalled accurately were calculated. Interrater reliability (mean Cohen's Kappa) was 0.96 for coding responses to the recall questions.

Background characteristics and medical details

Socio-demographic variables like age, gender and education were assessed by a self-reporting questionnaire. Nurses or physicians provided medical details for each patient enrolled in the study, including, diagnosis and treatment intent (curative or palliative).

Current levels of generalized anxiety were measured with the shortened, Dutch version of the State-Trait Anxiety Inventory (STAI) (Spielberger, 1983; Stanley, Novy, Bourland, Beck, & Averill, 2001; van der Ploeg, Defares, & Spielberger, 1980). Respondents indicated their level of agreement (from 'not at all' to 'very much so' on a 4-point Likert scale) to each of the items, with raw scores summed to produce a total score (10-40) and higher values representing higher levels of anxiety. This scale demonstrates good reliability and validity and has been used widely in cancer populations. Cronbach's Alpha for the scale was 0.90 in this sample.

Statistical analysis

To determine differences between participants and non-responders, Chi-square (χ^2) tests and independent sample t-tests were used. We explored the

influence of emotional and informational cues and the nurses' subsequent responses on the amount of information patients recalled. In the current data there is a nested structure captured by a three-level hierarchy. The measurements of patients (first level) are nested in nurses (second level) and hospitals (third level). We therefore used multilevel regression analysis with a random intercept to control for clustering. Throughout, effects were tested using two-sided Wald tests. The first regression analysis examined the effect of patients' emotional and informational cues on recall. In Model 1, the background characteristics (age, anxiety, gender and education) were introduced. In Model 2, emotional cues and informational cues were added. To control for consultation duration and amount of information discussed, these variables were introduced to the final model. Second, to establish the effect of the nurses' responses on recall, we conducted two separate regression analyses, one for responses to emotional cues (i.e. exploration, acknowledgement, 'minimal' encouragement and distancing) and one for responses to informational cues (exploration, appropriate information giving, inappropriate information giving and distancing). These analyses were the same as for the cues, but this time the responses were added in Model 2. To increase interpretability of the regression coefficients, all continuous variables were centred. The number of missing values was limited, as a researcher was present in the room and checked if all questions were answered. If items from multi-item scales were still missing, the sum score was transformed to the full-item equivalent if at least 75% of the items from the scale were completed. Analyses were performed with SPSS (version 16.0; SPSS Inc, Chicago, Ill) and MLwiN 2.10 (Rasbash et al., 2000) and the results were considered statistically significant when $p < .05$.

Results

Recruitment and sample

Of 283 eligible patients, 182 patients (64%) gave informed consent to videotape the consultation; 101 patients refused to participate: 60 felt it was too much, 19 did not want their consultation to be videotaped, 10 felt too sick or too tired, and 12 refused for other reasons or without giving a reason. Non-participating patients were older (mean age 73.7, SD=6.8) than participating

patients (mean age 72.2, SD=4.8; $p<0.05$). Participants and non-participants did not differ in gender. Forty-four participants were excluded because they belonged to the experimental group in the post-test. Of the resulting patients, 105 completed the recall questionnaire (82%); their characteristics are given in Table 5.2.

Table 5.2 Patient characteristics (n=105)[†]

	N	%
Gender		
Female	34	32.4
Male	71	67.6
Age		
Mean (range)	72.4 (65.0-85.7)	
SD	4.9	
N	105	
Educational level		
Low	47	44.8
Middle	23	21.9
High	34	32.4
Diagnosis		
Digestive/gastrointestinal	41	39.0
Lung	24	22.9
Genitourinary	14	13.3
Breast	9	8.6
Haematologic/blood	10	9.5
Gynaecologic	5	4.8
Other	1.0	1.0
Treatment goal		
Curative	22	21.0
Palliative	62	59.0
Time since diagnosis (months)		
Median (range)	1.4 (0-216)	
N	101	
State Anxiety [§]		
Mean (range)	20.6 (10-38)	
SD	5.7	
N	102	
Consultation duration		
Mean (range)	55.9 (15.4-93.5)	
SD	14.3	
N	105	

Table 5.2 Continued

	N	%
Amount of information presented		
Mean (range)	80.8 (32-127)	
SD	20.6	
N	105	
Recall (absolute)		
Mean (range)	7.2 (0-17.0)	
SD	3.8	
N	105	
Recall (proportion) [¶]		
Mean (range)	21.9 (0-72.7)	
SD	11.8	
N	105	

[†]Numbers do not always add up to 105 or 100% due to missing values

[§]Normal range: 10-40, higher scores indicate greater anxiety

[¶]Normal range: 0-100%

Overview of cues and responses

Patients gave more informational cues than emotional cues (Table 5.1). Eleven patients (10.5%) did not express any emotional cues, one no informational cues (1.0%) and one patient (1.0%) did not express any cues at all. We looked at the median and average number of cues expressed in all videotaped consultations, including those in which no cues were given. Patients gave a median number of 4 and mean number of 6.4 emotional cues per consultation (SD=6.2; range 0-27) whereas they expressed a median number of 11 and mean number of 13.9 informational cues per consultation (SD=10.6; range 0-69).

The most common response to emotional cues was distancing (35.8%), followed by acknowledgement (29.5%). Nurses responded to the majority of the informational cues (65.7%) by giving appropriate information.

Amount of information discussed and recall

For the 105 patients who completed the recall questionnaire, the content of the whole consultation was coded. On average, nurses discussed 80.8 items, of which 36.6 items were recommendations about side effects (Table 5.2). Patients remembered a mean number of 7.2 recommendations (21.9%).

Table 5.3 Final step in the regression analysis of the influence of nurses' responses to emotional cues and informational cues on % information recall (n=102)[†]

	On emotional cues			On informational cues		
	B	SE	p	B	SE	p
Background characteristics						
Age (years)	-0.14	0.26	0.60	-0.20	0.26	0.53
Anxiety (STAI) [‡]	0.22	0.19	0.26	0.14	0.20	0.47
Gender (male)	6.11	2.44	0.01**	7.00	2.53	0.01**
Education (lower) [§]						
Middle	1.25	2.63	0.64	-0.16	2.65	0.95
Higher	5.33	2.36	0.02*	3.25	2.50	0.19
Responses						
'Minimal' encouragement	1.05	0.56	0.06	-	-	-
Acknowledgement	0.45	0.63	0.95	-	-	-
Exploration	-0.65	1.00	0.70	2.14	1.40	0.12
Distancing	-0.81	0.33	0.02*	-1.62	1.42	0.25
Adequate information	-	-	-	0.24	0.19	0.21
Inadequate/insufficient information	-	-	-	-0.10	0.31	0.74
Consultation characteristics						
Total amount of information discussed	-0.16	0.07	0.02*	-0.12	0.07	0.07
Consultation duration (minutes)	0.10	0.09	0.26	0.07	0.09	0.42

SE indicates standard error

[†] *three patients did not fill out the anxiety questionnaire, therefore n=102*

[‡] *Higher scores indicate greater anxiety*

[§] *Denotes dummy coded variable with reference group in brackets*

**p<0.05*

***p<0.01*

****p<0.001*

Impact of cues and responses on recall

The expression of neither emotional nor informational cues was associated with recall (not in Table). However, the way nurses responded to emotional cues influenced patient recall in two ways; distancing responses negatively influenced recall (B=-0.81, p=0.02) whereas there was a marginally significant positive effect of 'minimal' encouragements (B=1.05, p=0.06) on recall (Table 5.3). This suggests that the more nurses responded to emotional cues by providing 'minimal' encouragements (e.g. 'Hmmm', 'Go on'), the more the

patient remembered. In contrast, when the nurses distanced themselves from emotional cues e.g. by ignoring them or switching the topic, patients remembered less. These effects were similar when using absolute rather than proportion recall. Furthermore, patients recalled less when they were male (e.g. model with responses to emotional cues; $B=6.11$, $p=0.01$), and when less educated (model with responses to emotional cues; $B=5.33$, $p=0.02$). Finally, when more information was presented in the consultation patients remembered proportionally less (model with responses to emotional cues; $B=-0.16$, $p=0.02$). Nurses' responses to informational cues were not associated with recall.

Discussion and conclusion

Discussion

The impact of nurses' responses to emotional cues on recall

In this study we used sequence analysis of cancer patients' cues and nurses' responses to look at their effects on patients' recall. Sequence analysis is relatively new in communication research and it may give a more precise picture of the complex dynamics of the interaction between a patient and his or her clinician than more traditional correlational methods (Del Piccolo, Mazzi, Dunn, Sandri, & Zimmermann, 2007; Eide et al., 2004; Uitterhoeve et al., 2007; Zimmermann et al., 2007).

Our main finding is that the responses of nurses to emotional cues influenced patients' recall. The more 'minimal' encouragements nurses gave, the more information patients recalled, while distancing responses resulted in lower recall scores. These effects were similar for proportional and absolute recall. 'Minimal' encouragement responses included back channelling (e.g. 'Yes...', 'Hmmm'), agreement ('Right', 'Go on') and functional silence. It is important to note that if non-verbal aspects of the response (e.g. body posture or tone of voice) signalled that the nurse was not picking up the cue but rather responded in an automated and uninterested manner, we coded the response as distancing and not 'minimal' encouragement. Previous studies have shown that health care providers often give 'minimal' encouragements after a patient exhibits a cue (Eide et al., 2004; Kim, Kols, Prammawat, & Rinehart, 2005;

Rimondini et al., 2006). 'Minimal encouragers' are unobtrusive and do not interrupt the flow of the patient conversation, but the 'Hmm' or 'Go on' is showing interest. This may encourage the patient to further express their concerns thereby creating a caring or positive context for the consultation (Eide et al., 2004) and informs the nurse about the patient's identity. Distancing responses by nature, are likely to achieve the exact opposite, they will shut down the patient's disclosure of further concerns and accounts of their 'life world' (Barry, Stevenson, Britten, Barber, & Bradley, 2001) and increase their distress. It is, however, important to keep in mind that the effect of the 'minimal' encouragement responses was merely a statistical trend ($p=.06$) and this finding should be replicated in a larger study with more statistical power.

The current findings support a recent communication model by Neumann and colleagues (2007). According to this model, socio-emotional communication, like responding to emotions, may improve patient outcomes via an affective-oriented path as well as a cognitive/action-oriented path. Firstly, it helps patients feel understood and supported (affective-oriented). Secondly, it will improve the informative aspects of the consultation by facilitating patients to reveal their concerns and facilitate the health providers' understanding of the patient's medical and psychological situation. As a result, the health provider is better able to attune information to the patient's needs (cognitive/action-oriented). The affective oriented path may result in better recall as when patients feel understood and supported they may be less anxious and more receptive to the information presented (Pickersgill & Owen, 1992). The cognitive/action-oriented path may result in better recall, as information that is personally relevant increases the patient's motivation to process and improves the likelihood that information is encoded and stored in memory. Neither patient anxiety nor the expression of emotional cues per se was associated with recall, rendering the first explanation of our results less likely.

It is unclear why two other types of responses to emotional cues that are commonly deemed adequate, acknowledgement and exploration (e.g. Zimmermann et al., 2008), did not improve patient recall. Only 10% of the responses were explorations, which is in itself an interesting finding as cues are by definition implicit, which will often mean that they require clarification

from the health care provider. This means that lack of statistical power may explain why we did not find a significant effect for this type of response. This argument does not hold for acknowledgment responses, as these were more common than 'minimal' encouragements. The aim of the consultations in the current study was to educate patients about chemotherapy treatment. As argued by Eide et al. (2004), in cancer contexts such as these, direct communication about fears and emotions may provoke distress and therefore be less beneficial for patient outcomes. Similarly, others' findings suggest that both not enough and too much focus on emotions may hamper effective communication (Schmid Mast, Kindlimann, & Langewitz, 2005). Our findings provide some evidence for such a curvilinear relation between emotional communication and outcomes of communication.

Nurses' responses to informational cues

We expected that if patients express informational cues and these are appropriately responded to by the nurse, they will be better able to direct the information flow, increasing their understanding of the information and consequently, they may also recall more (Dimoska, Tattersall, Butow, Shepherd, & Kinnersley, 2008; Harrington, Noble, & Newman, 2004; van der Meulen, Jansen, van Dulmen, Bensing, & van Weert, 2008). It is surprising therefore that neither patients' informational cues nor nurses' responses influenced recall. Patients may give informational cues because they have high needs for information or because they do not understand information presented to them, and this may influence recall differently. Alternatively, other aspects of participating behaviour may be more predictive of information recall than the number of informational cues expressed. For example, if a patient clearly voices his or her agenda, it may be easier for nurses to attune information hence reducing the need for patients to raise issues themselves (Timmermans, van der Maazen, van Spaendonck, Leer, & Kraaimaat, 2006). The vast majority of informational cues were responded to by giving appropriate information, which is in concordance with Butow et al. (2002). As there was little variation in the type of responses, we may have failed to establish their effect on recall.

Cue giving and responses by the nurse

Differences in the conceptualisation and measurement of cues, consultation

length, type of health professional (i.e. nurse versus doctor) and patient characteristics (e.g. age and disease severity) make it difficult to compare different studies on cue responding (Zimmermann et al., 2007). Bearing this in mind, patients in our study disclosed informational cues more often than emotional cues echoing findings by Butow et al. (2002). Eleven patients (10.5%) did not express any emotional cues, which is lower than the 23% and 68% reported in previous studies in oncology (Butow et al., 2002; Ford & Hall, 2004). In our study, patients expressed an average of 6.4 emotional cues and 13.9 informational cues (also including explicit questions) per consultation. In accordance with our results, an overview of the literature on patients' emotional cues and concerns report a mean frequency range of between 1-7 emotional cues per consultation (Zimmermann et al., 2007). In a study by Butow et al. (2002) patients expressed a mean of 1.3 emotional cues 2.3 informational cues and 9 questions. This study involved consultations with oncologists rather than nurses and the consultations were much shorter (on average 19 minutes) than the consultations in our study (on average 56 minutes), which may explain the discrepancy.

Regarding the responses to patients' emotional cues, two studies are directly comparable to our study, because they also used MIARS and studied nursing consultations (Heaven et al., 2006; Uitterhoeve et al., 2007). We found that nurses distanced themselves from 36% of the emotional cues (e.g. by switching the topic), acknowledged 30%, gave 'minimal' encouragements to 25%, and explored 10% of the cues. The category 'minimal' encouragement was added to the original MIARS protocol. When we exclude these responses, our results (49% distancing, 38% acknowledged 13% explored), are comparable with Heaven et al., (2006) who report 50% distancing, 29% acknowledged and 12% explored. However, these results are somewhat dissimilar from the study by Uitterhoeve et al., (2007) reporting 50% distancing but 17% acknowledgement and 32 % exploration. Because the study by Uitterhoeve et al. (2007) used a standardized patient (an actor) and the interviews in the study by Heaven et al. (2006) were explicitly aimed at identifying patients' concerns and emotions we cannot compare the number of cues expressed in these studies with our own results.

Limitations of this study

Some limitations of this study should be considered. Coding relatively rare events such as emotional cues and subsequent responses is challenging. The reliability of emotional and informational cues and the nurses' responses was moderate to good with one exception, the reliability of distancing responses to emotional cues proved insufficient. In the study by Uitterhoeve et al., (2007), distancing responses were coded with high reliability. However, in their study, all nurses communicated with the same standardized patient (an actor), meaning that their consultations were more uniform than the real life consultations in our study and therefore probably easier to code reliably. Furthermore, a study by Zandbelt and colleagues (Zandbelt, Smets, Oort, & de Haes, 2005) on patient-centred communication showed that the reliability of the facilitating dimension of the coding instrument that they developed was good to excellent, whereas the interrater reliability of the inhibiting dimension was only fair. Perhaps, inhibiting behaviours such as distancing responses to emotional cues are more difficult to judge, and further refinement of the coding criteria or additional training may be needed.

This study was limited to consultations with older cancer patients and should therefore be replicated in consultations with patients of all ages. However, the results are important for this patient group, since recall is more problematic for older cancer patients (Brown & Park, 2003; Jansen et al., 2008a) and the socio-emotional context of the consultation may assist them in processing and remembering the information presented (Hanoch et al., 2007; Lockenhoff & Carstensen, 2004). As we included only older patients in this study, future studies are needed to establish whether or not the effect of responses to emotional cues on recall is stronger for older cancer patients. Of course, not all cues necessarily need to be responded to or need to be responded to in the same way. Qualitative studies may help identify the appropriateness of responses to cues of different content and intensity.

Conclusion

Patients are clearly responsive to how nurses address their emotions. Previous studies have shown that emotional dimensions of communication influence affective outcomes of consultations in cancer care (Fogarty, Curbow, Wingard,

McDonnell, & Somerfield, 1999; Schofield et al., 2003); this study adds that they also influence cognitive outcomes such as recall.

Implications for practice

Health care professional's communication training should include attending to patient's cues particularly emotional cues, as this has an effect on information recall and may influence adherence to treatment not only in cancer care but possibly also in other chronic diseases.

A large, light gray number '6' is the central graphic element. It is filled with a complex pattern of thin white lines that form various geometric shapes, including circles, squares, and triangles, creating a grid-like or architectural feel. The number is positioned on the left side of the page.

6

The role of companions in aiding
older cancer patients to recall
medical information

Abstract

Objectives. This study investigates information recall in unaccompanied and accompanied older cancer patients and their companions. **Methods.** One hundred cancer patients (aged ≥ 65 years) and 71 companions completed a recall questionnaire after a nursing consultation preceding chemotherapy treatment. Recall was checked against the actual communication in video recordings of the consultations. Patients also completed measures of anxiety and memory-related beliefs. **Results.** Findings revealed that recall in patient and companion couples together was higher than their separate recall scores (both proportional and absolute), indicating that they supplement each other. Proportionally, unaccompanied patients recalled almost as much as couples, whereas their absolute recall scores were lower. Younger age and higher education were associated with higher recall in both patients and companions. Patients' memory-related beliefs predicted the recall scores of their companions rather than their own recall score. When patients reported memory complaints, recall was lower in their companion. In contrast, when patients indicated that they did not understand all information, their companion recalled more. **Conclusions.** These findings indicate that, although an interrelationship exists between recall in patients and their companions, accompanied patients are likely to benefit from the extra information that their companions remember.

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Introduction

During healthcare visits most older patients are accompanied by significant others such as a spouse or adult child (Clayman, Roter, Wissow, & Bandeen-Roche, 2005; Eggly et al., 2006; Glasser, Prohaska, & Gravdal, 2001; Shields et al., 2005). Companions may facilitate, inhibit or impede patient participation and autonomy (Adelman, Greene, & Charon, 1987; Beisecker, 1989; Clayman et al., 2005; Hasselkus, 1992). In oncology, companions are more likely to be present at initial visits, immediately after cancer recurrence, and in the terminal phase of the disease rather than in a routine follow-up (Merckaert, Libert, Delvaux, & Razavi, 2005). Apart from reduced patient participation (Greene, Majerovitz, Adelman, & Rizzo, 1994), emotional support from doctors (Labrecque, Blanchard, Ruckdeschel, & Blanchard, 1991) and shared decision-making (Greene et al., 1994), the presence of companions has been found to increase patient understanding, involvement in the consultation, and decision-making (Clayman et al., 2005). Others found no effects at all (Shields et al., 2005). A study in a geriatric oncology setting showed that companions' roles include providing emotional support, transcribing information, assisting in decision-making, providing companionship, elaborating on patients' comments, advocating for the patient, interpreting information for the patient, and acting as a memory aid (Ellingson, 2002). Similar roles have been reported by other studies (Beisecker, 1994; Glasser et al., 2001; Schilling et al., 2002).

One reason older patients are accompanied to consultations is to help them understand and remember information provided by the health professional (Clayman et al., 2005; Ellingson, 2002; Glasser et al., 2001; Schilling et al., 2002). For older patients, bringing a companion to consultations is a potentially useful compensation tool for memory decline (Gould, Osborn, Krein, & Mortenson, 2002; Johansson, Andersson, & Ronnberg, 2005). It is well established that as people age; they experience declining cognitive function (Bopp & Verhaeghen, 2005; Grady & Craik, 2000; Salthouse, 1996) and more difficulty remembering medical information (Brown & Park, 2003). Of course, age does not exist in a vacuum. Factors such as gender, anxiety, level of education, and disease severity may interact with age to influence recall, or affect recall over and above the effect of age. Also, an interrelationship could exist between recall of information in patients and their companions. Recall

scores of patients and their companions may be similar or dissimilar depending on for example the relationship between patient and companion (e.g. spouse or child). Beliefs people hold about their memory functioning can influence their memory performance (Hess, 2005; Neupert & McDonald-Miszczak, 2004). When people have to remember information together, beliefs about their own cognitive abilities and beliefs of their partners' abilities influences whether they actively process information or (more or less) rely on their partner to remember information (Berg et al., 2007). Recall of medical information is important for older patients because they should have sufficient comprehension to make informed choices, correctly follow treatment regimens and recognize side effects that require medical attention. Also, lower recall has been identified as an important factor explaining non-adherence to treatment (Kessels, 2003; Ley, 1982). As the care of oncology patients is now primarily carried out at home, there is an increased reliance on caregivers (Haley, 2003), and some have even suggested that compliance with treatment is often more dependent upon caregivers than patients (Beisecker, Brecheisen, Ashworth, & Hayes, 1996). Altogether, this clearly suggests the importance of investigating information recall in both patients and their companions.

The purpose of this study is to: 1) examine the influence of companion presence on recall of information presented to older cancer patients by nurses in an educational session preceding chemotherapy treatment 2) assess differences in (predictors of) recall between patients and companions, and 3) explore if patient and companion characteristics influence one another's recall.

Materials and methods

Participants

Consecutive new patients in 10 Dutch hospitals were recruited between February 2005 and July 2007. The Medical Ethical Committee of the University Medical Centre Utrecht, the Netherlands, granted permission for the study supplemented by local feasibility statements from all participating hospitals.

To be eligible for the study, patients had to meet the following inclusion criteria: (a) aged 65 years or older, (b) receiving chemotherapy for the first time or for the first time in 5 years, (c) not participating in a Phase III clinical trial, (d) sufficient command of the Dutch language, and (e) no cognitive impairment (indicated in the medical record).

This study was part of a larger study investigating the effects of communication skills training. After pre-test, hospitals that participated in the study were randomized to receive communication training. As part of this training, nurses practised addressing the needs of patients as well as their companions. Because we think that this may influence the relation between accompaniment and recall of information, patients from the experimental hospitals at post-test were excluded (n=25).

Procedure

Before the consultation, written informed consent to videotape the consultation was given by patients and nurses. Immediately after the consultation, patients completed a questionnaire including, background and disease characteristics, anxiety, recall and memory-related beliefs. The companion identified as providing the greatest assistance in daily life, was also asked to complete the recall questionnaire. A researcher was available to read the questions aloud, if necessary. If this was the case, patient and companion completed the recall questionnaire in separate rooms. Additional data was obtained on companions' age, gender and level of education.

Measurements

Recall of information

Video observations

The videotapes were analysed using an observation checklist developed for this study that is described extensively elsewhere (Jansen et al., 2008b). An information item was defined as a segment of speech expressing a single idea concerning treatment and disease-related issues (Dunn et al., 1993). The categories in the checklist covered two main domains: (a) information about treatment and related issues (e.g. treatment details and cancer-specific

information) and (b) recommendations on handling potential side effects (e.g. diet and hygiene). Additional elements discussed, but not included in the standard checklist, could be added to each category of the checklist, resulting in complete content analysis of the consultation (i.e. total amount of information discussed).

Recall questionnaire

Recall was measured using a structured questionnaire, the 'Netherlands Patient Information Recall Questionnaire (NPIRQ)' that was developed in conjunction with the observation checklist (Jansen et al., 2008b). Items recalled in response to eleven open-ended questions about treatment recommendations were compared with items mentioned by the nurse during the videotaped consultation. The number (absolute recall) and percentage (proportion recall) of facts recalled accurately were calculated in total and for each category separately.

Coding reliability

Two coders were trained. Discrepancies during training were resolved through discussion. The main coder observed all consultations. The other coded a random 20% of the main coder's consultations. Interrater reliability (mean Cohen's kappa) was 0.79 (range, 0.05-1.0) for the content analysis of the videotapes and 0.96 (range, 0.87-1.0) for coding responses to the recall questions (Jansen et al., 2008b).

Pooling recall data

If patients and their companions remember different types of information, they remember more as a couple than each of them independently. Recall in the patient and companion couple was pooled by summing the number of items they each recalled on each recall question (Meudell, Hitch, & Kirby, 1992). For example if patient A recalled 5 items a-b-c-d-e and companion B recalled 5 items a-b-c-f-g, pooled recall for the AB couple will be 7 items a-b-c-d-e-f-g.

Background and medical details

Socio-demographic variables were assessed by a self-reporting questionnaire. Nurses or doctors provided medical details for each patient, including diagnosis and treatment goal (curative or palliative).

Anxiety

Current levels of generalized anxiety were measured with the shortened version of the Dutch adaptation of the State-Trait Anxiety Inventory (STAI, Spielberger, 1983; van der Ploeg, Defares, & Spielberger, 1980). Respondents indicated their level of agreement (from 'not at all' to 'very much so' on a 4-point Likert scale) to each of the items, with raw scores summed to produce a total score (10-40). Cronbach's alpha for the scale was 0.87.

Memory-related beliefs

Four questions were used to assess memory-related beliefs regarding the videotaped consultation using a 4-point Likert scale. Patients were asked to rate their level of attention during the consultation, their level of understanding of the information discussed and their perceived likelihood of remembering the information. Because of the skewed distribution, scores on the attention question were dichotomized into 'high level of attention' (score 1) and 'not a high level of attention' (scores 2-4). Likewise, scores on the likelihood of remembering question were dichotomized into 'highly likely to remember' (score 1) and 'not highly likely to remember' (score 2-4). For the level of understanding question, patients only used two of the four response options ('high level of understanding' and 'moderate level of understanding'). In addition, subjective memory complaints were assessed using the memory question of the Groningen Frailty Indicator (GFI, Schuurmans, Steverink, Lindenberg, Frieswijk, & Slaets, 2004) ('do you have any complaints about your memory?'; 3-point Likert scale) and the European Organization for Research and Treatment of Cancer (EORTC) Quality of Live Questionnaire (QLQ-C30) (Aaronson et al., 1993; 'in the last week, did you have difficulties remembering things?'; 4-point Likert scale). A dichotomous memory composite score was computed; 'no memory complaints' consisting of patients that indicated that they did not have any problems with their memory on both the GFI question and the EORTC question and 'memory complaints' consisting of the remaining patients.

Statistical analysis

To determine differences between participants and non-responders and patients with and without a companion, Chi-square (χ^2) tests and independent

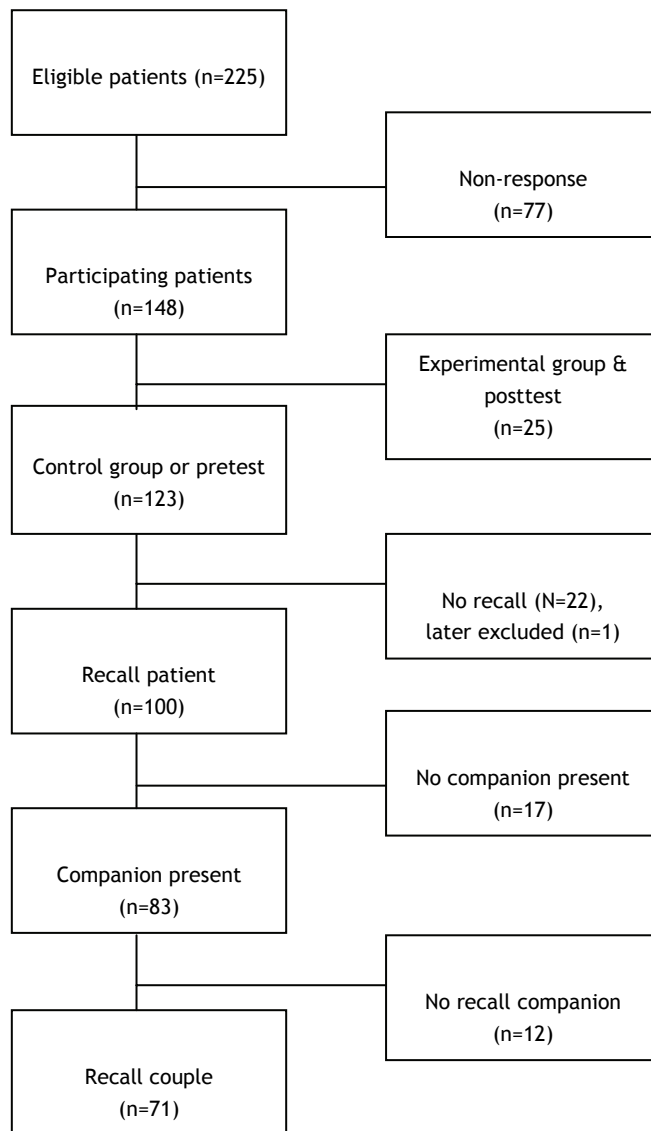
sample t-tests were used. Differences in recall between unaccompanied patients, accompanied patients, companions and the pooled data were tested using independent- and paired sample t-tests.

To assess the effect of companions and patients on one-another's information recall, the Actor-Partner Interdependence Model (APIM) was used (Kenny, Mannetti, Pierro, Livi, & Kashy, 2002). The APIM is appropriate when a dyad (i.e. patient-companion couple) is the unit of analysis and tests need to be performed both within and between dyads (Kenny, 1996). The heart of the APIM approach is to assess effects for both the actor and his or her partner. Use of the APIM allows one to assess not only whether an actor's own attributes predict his or her responses but also whether the attributes of the actor's partner predict the actor's responses while the impact of the actor's own attributes is controlled for (Kenny et al., 2002). In the current study, the actor effect estimates the effect that an actor's own score on the independent variable has on that person's outcome measure (e.g. either patient's age influencing his or her own recall or companion's age influencing his or her own recall). The partner effect estimates the effect that scores of the partner on the independent variable have on the actor's outcome (e.g. patient's age influencing companion's recall or companion's age influencing patient's recall). In the model, not only actor and partner effects of variables can be tested but several interactions involving actor and/or partner variables.

The APIM was tested, as recommended by Campbell and Kashy (2002) , within a multilevel regression analysis. A unique feature of multilevel analysis is that it works with a specific statistical model designed for nested data. In the current data there is a nested structure captured by a two-level hierarchy. The measurements of patients and companions (first level) are dependent and nested in a couple (second level). Couples are also nested with nurses (third level) and hospitals (fourth level) but since no variance in recall was found at these levels (i.e. Intraclass Correlation was 0.000 for both levels) we used a two level model for the analysis. The following models were tested. Model 1 was a simple model with the variables individual (patient or companion) and relationship between patient and companion (spouse or adult child). In Model 2, the background characteristics (gender, age and education) of the actor and the partner were introduced. To test whether there were different predictors

of recall for patients and companions, interactions between individual (patient or companion) and the significant background characteristics were added. In Model 3, memory-related beliefs were introduced. Since no companion data was obtained for these variables, only the actor effect on the patient's outcome and the partner effect on the companion's outcome could be assessed. The final Model (Model 4) examined all the significant predictors of the previous models. To control for patient anxiety, treatment goal, consultation duration and amount of information discussed, these variables were introduced to the final model, step by step. The analysis revealed a quadratic, rather than linear, relationship between percentage recall and the total amount of information presented. To account for this non-linearity, a second-order polynomial regressor (quadratic) was used for this variable (Fox, 1997). To increase interpretability of the regression coefficients and because interaction terms were modelled, all continuous variables were centred (Hox, 2002) using the recommended approach for APIM. Analyses were performed with Statistical Package for the Social Sciences (SPSS; version 16.0; SPSS Inc, Chicago, Ill) and MLwiN (Rasbash et al., 2000).

Figure 6.1 Flowchart of participants



Results

Participants

Figure 6.1 depicts a flowchart of the inclusion of patients in this study. A sample of 225 patients was recruited. Of these, 148 patients (66%) gave informed consent to videotape the consultation; 77 patients refused to participate: 46 felt it was too much, 14 did not want to be videotaped, 5 felt too sick or too tired, 12 refused for other reasons or without giving a reason. Participants and non-participants did not differ in gender or age. Twenty-five participants were excluded because they belonged to the experimental group in the post-test.

One hundred and one of the resulting 123 patients (82%) completed the recall questionnaire. One patient was later excluded because he or she was assisted in completing the questionnaire, leaving 100 patients. Patients with and without a recall questionnaire differed in gender ($\chi^2(1) = 6.34, P < .05$), patients who completed the recall questionnaire were more likely to be male. There was no difference in age. Eighty-three of the patients who completed a recall questionnaire were accompanied to the consultation, 71 of these companions (86%) filled out the recall questionnaire.

Patient and companion characteristics

Patient characteristics are shown in Table 6.1. Eighty-six percent of the patients were accompanied to the consultation, the majority (76%) by one companion. There was a significant gender difference ($\chi^2(1) = 4.67, P < .05$) and difference in living arrangements ($\chi^2(1) = 9.71, P < .01$) between patients with and without a companion. Unaccompanied patients were more often men, and more often lived alone. Consultations were longer when a companion was present ($M=57.37; SE=1.41$) than when patients were alone ($M=49.07; SE=4.00, t(106) = -2.26, P < .05$) and nurses discussed more information in accompanied ($M=83.60; SE=2.21$) versus unaccompanied ($M=69.94; SE=5.01, t(99) = -2.58, P < .05$) consultations. Finally, unaccompanied patients more often indicated that their level of attention during the consultation was high compared with accompanied patients ($\chi^2(1) = 3.88, P < .05$). No other significant differences were found.

Table 6.1 Characteristics of patients with and without companion^{†‡}

		With companion		Without companion	
		N	%	N	%
Number of patients		106	86.2	17	13.8
Gender*	Female	41	38.7	2	11.8
	Male	65	61.3	15	88.2
Age	Mean (range)	72.1 (65-85.7)		72.8 (65.5-81.9)	
	SD	4.6		4.7	
	N	106		17	
Educational level	Low	54	52.4	7	41.2
	Middle	22	21.4	2	11.8
	High	27	26.2	8	47.1
Living arrangements**	With spouse/ children	84	81.6	8	47.1
	Alone	19	18.4	9	52.9
Children	Yes	91	89.2	12	70.6
	No	11	10.8	5	29.4
Diagnosis	Digestive/ gastrointestinal	47	44.3	4	23.5
	Lung	25	23.6	5	29.4
	Genitourinary	11	10.4	2	11.8
	Breast	9	8.5	1	5.9
	Haematologic	9	8.5	3	17.6
	Gynaecologic	4	3.8	2	11.8
	Other	1	0.9	0	0.0
Treatment goal	Curative	24	29.6	3	20.0
	Palliative	57	70.4	12	80.0
Time since diagnosis (months)	Mean (range)	7.9 (0.03-135.2)		32.2 (0.3-219.2)	
	SD	20.4		71.2	
	N	94		15	

Table 6.1 Continued

		With companion		Without companion	
		N	%	N	%
State Anxiety [§]	Mean (range)	21.5 (10-38)		20.5 (10-30)	
	SD	6.4		4.8	
	N	97		17	
<i>Memory-related beliefs</i>					
Subjective memory complaints	No	59	55.7	10	58.8
	Not no	47	44.3	7	41.2
Perceived level of attention*	High	59	70.2	15	93.8
	Not high	25	29.8	1	6.2
Likelihood of remembering	High	33	39.8	10	62.5
	Not High	50	60.2	6	37.5
Perceived level of understanding	High	66	78.6	15	93.8
	Moderate	18	21.4	1	6.2
<i>Consultation characteristics</i>					
Consultation duration (minutes)*	Mean (range)	57.4 (34.1-93.5)		49.1 (50.4-90.0)	
	SD	13.4		16.5	
	N	91		17	
Amount of information total*	Mean (range)	83.3 (44.5-127)		69.9 (33-100)	
	SD	19.7		20.6	
	N	83		17	

[†]Numbers do not always add up to 123 due to missing values

[‡]Tested for differences between patients with and without a companion

* $P < .05$, ** $P < .01$

[§]Normal range: 10-40, higher scores indicate greater anxiety

Patients were most often accompanied by their spouse (66%). For couples that completed the recall questionnaire, differences between patient and companion were tested (not in Table). Patients were significantly older compared with child-companions and spouse-companions (patient $M=71.57$; $SE=0.64$ versus spouse, $M=68.38$; $SE=1.14$, $t(81) = 2.55$, $P < .05$; patient $M=74.1$; $SE=1.76$ versus adult child $M=44.51$; $SE=1.51$, $t(41) = 15.97$, $P < .001$). Furthermore, there was a significant gender difference between patients and

companions if the companion was the patient's spouse ($\chi^2 (1) = 34.10, P < .001$). As the majority of patients were men, spouse companions were more likely to be women. Also, companions who were an adult child of the patient were more highly educated than the patient ($\chi^2 (2) = 13.55, P < .01$).

Table 6.2 Recall of recommendations: patients, companions and pooled data

Category ^a	No. of patients (without companion) ^b	Patient without companion recall (% (SD))	No. of Patients/companions ^b	Patient recall (% (SD))	Companion recall (% (SD))	Pooled recall (% (SD))
<i>Total recall (absolute)</i> <i>c3, d3, f3</i>	17	6.7 (2.3)	71	6.9 (4.0)	7.9 (4.7)	11.4 (5.5)
<i>Total recall (%)</i> <i>c3, d3, e1</i>	17	28.0 (17.0)	71	20.1 (10.0)	23.3 (12.7)	33.0 (13.4)
<i>Side effects</i>						
Skin and hair <i>c3, d3</i>	15	44.1 (32.4)	67	32.5 (30.1)	33.6 (30.1)	43.2 (30.6)
Mouth <i>c3, d3</i>	15	30.4 (31.2)	68	25.4 (23.1)	27.1 (26.5)	40.4 (25.7)
Digestive system <i>c3, d3, e1</i>	16	27.8 (23.7)	69	19.3 (14.6)	24.4 (19.6)	31.7 (20.0)
Stools <i>c1, d2, e1</i>	10	30.0 (42.2)	50	29.9 (39.7)	19.7 (33.3)	35.6 (41.1)
Eating and drinking <i>c3, d3 e2</i>	15	29.0 (30.8)	65	19.1 (16.2)	26.7 (22.4)	33.5 (23.1)
Hygiene <i>c3, d3</i>	13	42.4 (29.5)	66	23.1 (21.0)	27.1 (21.1)	38.9 (22.1)
General well-being and fatigue <i>c3, d3</i>	12	34.7 (37.2)		24.3 (28.9)	24.6 (26.1)	36.3 (31.0)

Table 6.2 Continued

Category	No. of patients (without companion) ^b	Patient without companion recall (% , (SD))	No. of Patients/ companions ^b	Patient recall (% , (SD))	Companion recall (% , (SD))	Pooled recall (% , (SD))
<i>Miscellaneous</i>						
Psychosocial issues ^{c1, d2}	8	12.5 (35.4)	35	24.1 (36.1)	13.3 (28.3)	32.4 (38.3)
Daily life ^{c1}	5	50.0 (50.0)	26	11.5 (29.4)	26.9 (49.5)	32.7 (52.8)
Side effects to report ^{c3, d3}	17	24.1 (31.5)	71	16.9 (15.1)	20.1 (15.6)	29.6 (18.7)

^a Recall for the different categories was calculated over all consultations in which at least one item from the category was discussed; differences between companion and pooled recall were only tested for total recall (% and absolute)

^b Refers to the number of consultations in which at least one item from the category was discussed

^c Refers to differences in recall between patient and pooled data

^d Refers to differences in recall between companion and pooled data

^e Refers to differences in recall between patient and companion

^f Refers to difference in recall between unaccompanied patient and pooled recall

¹P < .05; ²P < .01; ³P < .001

Recall

Pooled recall

To explore if patients and companions supplemented each other in the type and amount of information they recalled, their recall data were pooled. As Table 6.2 shows, couples recalled significantly more information (proportional, $M=33.00$; $SE=1.59$; absolute, $M=11.35$; $SE=0.66$) than the individual patient (proportional, $M=20.09$; $SE=1.19$, $t(70) = -12.33$, $P < .001$; absolute, $M=6.92$; $SE=0.47$, $t(70) = -11.50$, $P < .001$) or companion (proportional, $M=23.32$; $SE=1.50$, $t(70) = -10.87$, $P < .001$; absolute, $M=7.92$; $SE=0.56$, $t(70) = -10.13$, $P < .001$) on their own. Table 6.2 also depicts recall of the patients who came to the consultation alone. There was trend showing that unaccompanied patients ($M=28.00$; $SE=4.13$) recalled proportionately more information than accompanied patients ($M=20.09$; $SE=1.19$, $t(19) = 1.84$, $P < .08$), but absolute

recall did not differ. More importantly, although patients and companions together remembered more than each of them separately, the proportion recalled by the couples ($M=33.00$; $SE=1.59$) did not significantly differ from the proportion recalled by the unaccompanied patients ($M=28.00$; $SE=4.13$, $t(86) = -1.31$, $P > .05$). However, when looking at the absolute recall scores, pooled recall was significantly higher ($M=11.35$; $SE=0.66$) than recall in the unaccompanied patients ($M=6.68$; $SE=0.71$, $t(47) = -4.84$, $P < .001$).

Actor partner analyses

A two-level model predicted recall significantly better than a one-level model ($\chi^2(1) = 10.87$, $P < .001$), warranting multilevel regression analysis. The Intraclass Correlation was 0.38 for the initial model indicating that there was a significant and fairly strong relationship between patient and companion recall.

Background characteristics (Model 1 and 2)

The first model (see Table 6.3) shows that companions recalled more information than patients ($B = 3.323$, $P < .05$) and adult child companions recalled more than spouse companions ($B = 5.537$, $P < .01$). However, these differences disappeared in successive models. After introducing background characteristics (age, gender and education) of the actor and the partner, both age and education appeared to be significantly related to information recall in patients and companions (Model 2). Recall was lower when the person was older ($B = -0.300$, $P < .01$), and when less educated ($B = 7.225$, $P < .01$). To check whether effects differed for patients and companions, the interactions between the background variables and the variable individual (0=patient, 1=companion) were tested. These interactions were not significant, indicating that the effects of age and education were the same for patient and companion. Additionally, none of the background variables of the partner were significant.

Table 6.3 Summary of the Actor Partner Interdependence Model analysis for patient and companion recall†

	Model 1		Model 2		Model 3		Model 4	
	B	(SE)	B	(SE)	B	(SE)	B	(SE)
Individual (0 = patient 1 = companion)	3.323*	(1.530)	-3.217	(2.409)	1.071	(2.810)	1.264	(2.255)
Relationship (0 = spouse 1 = adult child)	5.537**	(2.305)						
Actor age			-0.300**	(0.100)			-0.317**	(0.104)
Actor gender (0 = male, 1 = female)			1.235	(2.844)				
Actor education (0 = low)§***								
Middle			3.571	(2.501)			2.728	(2.231)
High			7.225**	(2.533)			6.846**	(2.267)
<i>Effects of memory-related beliefs on companion recall (partner)</i>								
Memory complaints (0 = no 1 = not no)					-6.884**	(2.869)	-6.642**	(2.815)
Perceived level of attention (0 = high 1 = not high)					-9.046**	(3.426)	-2.141	(3.074)
Perceived level of understanding (0 = high 1 = moderate)					12.751***	(4.105)	7.603*	(3.634)
Likelihood of remembering (0 = high 1 = not high)					5.766	(3.036)		

†Interactions between individual and background characteristics were not significant and are therefore not shown in this Table

§ Effect tested using Chi-square (χ^2) test statistic

*P<.05, ** P<.01, ***P<.001

Memory-related beliefs (Model 3)

To look at the actor and partner effects of memory-related beliefs, these variables were introduced in Model 3. As companions did not complete these measures, only the actor effect on the patient's outcome and the partner effect on the companion's outcome could be assessed. Both patients' memory complaints and level of attention were negative predictors of companion recall. Companions whose partner (i.e. the patient) reported to have memory complaints, recalled less information themselves ($B = -6.884, P < .01$). Companions recalled less information if the patient indicated that their level of attention during the consultation was not high ($B = -9.046, P < .01$). In contrast, if the patient indicated that they had a moderate (compared with high) level of understanding of the information presented, companions recalled more information ($12.751, P < .001$). None of the actor effects were significant.

Final Model (Model 4)

In the final model, all variables that were significant in the previous models were introduced together. This model confirmed that recall was lower for older patients and companions ($B = -0.317, P < .01$) and higher for patients and companions with a higher level of education ($B = 6.846, P < .01$). Patients' memory complaints remained negatively and patients' subjective level of understanding positively associated with companion recall.

The introduction of possible confounding variables (patient anxiety, treatment goal, consultation duration and amount of information discussed) did not result in significant changes, although it did reveal a negative effect of amount of information discussed (quadratic: $B = -0.006, P < .01$). The more information nurses discussed, the less information patients and companions recalled with the significant negative quadratic component indicating that percentage recall deteriorates more rapidly when increasing amounts of information are discussed.

Discussion

The results of this study show that joint recall (both proportional and absolute) of couples was higher than patients' or companions' separate recall scores.

Apparently, cancer patients and their companions supplement each other in the type of information they remember. Pooled absolute recall was also higher than absolute recall in unaccompanied patients, but no such effect was found for proportional recall. Echoing previous findings (Labrecque et al., 1991), when companions were present consultations were on average 8 minutes longer and nurses discussed more information. This suggests that nurses are more selective in the information they give in unaccompanied visits, which may explain why unaccompanied patients recall almost an equal proportion of information on their own. It may also explain why there was a trend indicating that accompanied patients recalled proportionally less information than unaccompanied patients although there was no difference in absolute scores.

Alternatively, accompanied patients may put less effort into remembering all the information presented because they assume their partner will recall it for them (Johansson et al., 2005). This explanation is supported by the fact that unaccompanied patients reported higher levels of attention during the consultation than accompanied patients. Previous studies have shown that one reason patients bring a companion is to help them remember information (Clayman et al., 2005; Ellingson, 2002; Glasser et al., 2001; Schilling et al., 2002). Perhaps patients who choose not to be accompanied do so partly because they expect not to need support in remembering information. To disentangle the effect of being accompanied versus the effect of patient characteristics associated with preference for being accompanied, a study design in which patients are randomly allocated to bring a companion or not is necessary (Shields et al., 2005). A companion was present in 86% percent of the consultations in this study. The majority of patients (76%) were accompanied by one companion, most often the spouse (66%). Confirming earlier studies, accompanied patients were more often women (Glasser et al., 2001). The fact that in almost a quarter of the consultations two or more companions were present is worth mentioning, because the presence of more than one companion may make the consultation increasingly more complex.

Patients who did not bring a companion were more likely to live alone than accompanied patients. Nevertheless, almost half of the unaccompanied patients (n=8) did live with a partner or child(ren). Older patients seem to have established preferences for including or excluding significant others from

medical consultations (Shields et al., 2005). Present results suggest that, where recall is concerned, health professionals should accommodate these preferences rather than encouraging all patients to bring a companion. A cancer diagnosis is stressful for patients as well as their significant others and the presence of family and friends may provide emotional support (Ellingson, 2002; Labrecque et al., 1991; Street & Gordon, 2008). A recent survey by Wolff et al. (2008) showed that accompanied patients were more satisfied with the communication and care provided by their physician than unaccompanied patients. In contrast, other authors reported that in some situations companions may negatively influence the encounter, especially if they strongly pursue their own agenda or interfere with the patient's communication (Beisecker, 1989; Greene et al., 1994; Ishikawa et al., 2005). The current study reveals that a more family-centred approach, attending to all persons present, may contribute to further understanding of accompanied encounters in oncology settings.

The APIM model was used to analyse the data, because this method allowed assessing the effect of patient and companion characteristics on their own recall scores, as well as the effect of their characteristics on their partner's recall scores. Our analysis showed that recall is lower for patients and companions with lower levels of education and for older patients and companions. Recall also decreased when increasing amounts of information were discussed. These findings are in line with previous studies (Jansen et al., 2008a). Interestingly, we found that although patients' beliefs about their memory ability were not related to their own recall scores, they were related to recall in their companion. When patients reported memory complaints, companion recall was lower. This may indicate that companions of patients with memory complaints had memory complaints themselves. The majority of companions completing the recall questionnaire were the patient's spouse (66%). While spouses were on average younger than the patient they accompanied, their average age was 68 years, making it not unlikely for companions to have memory complaints too. Analysis revealed that when patients indicated moderate rather than complete understanding of the information presented to them, their companions recalled more. This seems to be in apparent contrast with the previous finding. However, posthoc analyses showed that although patients with memory complaints were as likely to be

accompanied by a spouse as an adult child, there was a trend indicating that patients reporting a moderate level of understanding were more often accompanied by an adult child ($\chi^2 (1) = 4.80, P = .057$). The effect of companion recall on patient understanding may be explained by the child-companions' younger age and higher education. Perhaps these patients knew they would not understand all of the consultation, and asked their child to accompany them.

The current study has some limitations. Only a small number of patients in this study were unaccompanied ($n=17$), the current results are tentative and should be replicated in a larger study with more statistical power. The memory-related beliefs questions were intended to tap into patients' beliefs about their ability to attend to, understand, and remember information discussed in the consultation. Recall was measured directly after consultations but patients completed most of the memory-related questions subsequent to the recall questionnaire. Therefore, these responses could have been a judgment of learning. It would be interesting to take the memory-related beliefs of the companion into account, unfortunately, the design of the larger study did not allow collecting these data for companions. The study is also limited in that it did not include objective measurements of patients' cognitive function. However, patients with non age-related cognitive impairments (according to their medical record) were excluded, rendering it unlikely that patients with clear cognitive deficits such as dementia participated in this study. This was supported by measures of cognitive functioning in a sub sample of 30 patients, using the Dutch version of the Telephone Interview for Cognitive Status (Kempen, Meier, Bouwens, van Deursen, & Verhey, 2007), showing that none of them (except one patient who scored just one point below cut-off), fulfilled criteria for cognitive impairment. Since more than half of the patients reported memory complaints, it is very likely that patients and their companions may have had more subtle, age-related cognitive deficits. Finally, although this study showed beneficial effects of a companion's presence on recall as measured directly after the consultation, transfer of these effects to everyday functioning merits further study.

In summary, older cancer patients forget substantial amounts of the information presented in educational sessions about chemotherapy treatment

but patients who bring a companion to the consultation are likely to benefit from the extra information that their companion will remember. Future studies should investigate the complex dynamics of the nurse-companion-patient interaction, with the ultimate aim of improving outcomes for older cancer patients and their families.



7

Summary and discussion

Summary

What insights did we gain from these studies into older cancer patient-clinician communication? Or more specifically, how do age and communication influence recall? Before answering these questions, it is useful to first recapitulate the theoretical background and conceptual model that was introduced in Chapter 1, which will allow the discussion of the general findings from our study within this framework.

In Chapter 1, the life span model of Selection, Optimisation, and Compensation (SOC, Baltes & Baltes, 1990) was put forward promoting a multi-dimensional approach on age-related processes. According to the SOC model, aging is associated with both gains and losses and individuals can age successfully when they adapt their behaviour in response to age-related changes. In addition to the SOC model, an overview was presented of some of the cognitive, physical, psychological, and social dimensions of aging and how these may affect communication between older cancer patients and their clinician, and the patients' information recall. Some of these age-related changes clearly influence communication and recall in a negative way (e.g. cognitive and health decline), whereas others may compensate for these declines (e.g. improved emotion regulation). In this thesis, factors were investigated that are important in communication with older cancer patients, with a focus on how these factors impact upon subsequent information recall. To this end, we videotaped encounters between older cancer patients and their nurses in preparation for chemotherapy treatment and analysed the resulting data, employed secondary analysis on a dataset of audiotaped first consultations between cancer patients of all ages and their medical or radiation oncologist, and conducted a literature review. As the specific outcomes were extensively discussed in the previous chapters, the findings will be briefly summarized below before we discuss their impact for communication with older cancer patients. Throughout, recall is defined with respect to the information provided in the clinical consultation, unless stated otherwise.

In the first part of this thesis we explored how age influences communication between cancer patients and their clinician, and patients' subsequent recall, while at the same time looking at the importance of other age-related patient factors.

Patient education about treatment in cancer care: an overview of older cancer patients' needs

Chapter 2 reviewed the literature to explore age differences in cancer patients' need for information and support surrounding their treatment for cancer (Chapter 1, Figure 1.1, 2). We hypothesized that changes in goals and beliefs with age may result in age differences in cancer patients' needs for information and support. Perhaps the most important finding of this review is that not a single study could be identified that focused specifically on older cancer patients' needs. Studies were included in the review if some of the patients were older (i.e. 65 years or older) and the presence or absence of age differences was reported. The results indicated that although older patients prefer to receive information about the most important aspects of their illness and treatment, they are relatively less interested in knowing all the details. Furthermore, older patients seemed to have less prominent needs for information and support regarding the effect of cancer treatment on sexuality and body appearance than younger patients. Finally, older patients unequivocally reported lower needs for psychosocial support compared to younger patients.

Does age really matter? Recall of information presented to newly referred cancer patients

In Chapter 3, we assessed to what extent age influences communication between cancer patients and their medical or radiation oncologist (Chapter 1, Figure 1.1, 3a) and determined the influence of chronological age, other age-related factors and communication on patients' recall (Chapter 1, Figure 1.1, 3b - 3d). To achieve these aims, secondary analyses were conducted on data from an Australian patient sample (from here on, this study will be referred to as 'the Australian study'). We hypothesized that age is associated with differences in communication and recall, although other factors may be equally or more important. The results showed that compared to younger

patients, older cancer patients had a lower educational attainment, a poorer performance status, were more likely to receive treatment with a palliative rather than curative intent, had a worse prognosis, and were less anxious than younger patients. These findings thus confirmed the presence of age-related decline and changes. Contradicting our literature review, the results did not show any age differences in cancer patients' information needs or preferences. In general, patients preferred to be fully informed, regardless of age. However, older patients did ask fewer questions during the consultation. Recall indeed decreased with age, but only when the total amount of information presented by the oncologist and the consultation length were taken into account. This suggests that when the duration of the consultation was the same and equal amounts of information were discussed, older patients remembered less information than younger patients. Furthermore, the more information that was presented, the less patients recalled. Similarly, patients who asked more questions recalled proportionally less but this effect disappeared after the amount of information discussed in the consultation was controlled for. The study also showed some unanticipated findings. Recall was influenced by prognosis in two ways. Firstly, patients with a poorer prognosis recalled proportionally less. Secondly, the more information that was provided about prognosis, the less information patients proportionally recalled, regardless of their actual prognosis. None of the other information categories (diagnosis and treatment) had an effect on recall. Both of these effects could not be explained in terms of patient anxiety.

In the second part of this thesis, we focused solely on information recall in older cancer patients. In terms of the SOC model, the emotional context of the consultation and the presence of a companion may compensate for age-related cognitive and physical decline. We aimed to examine if and how these two aspects of communication, influence recall. A study was conducted (from now onward referred to as 'the Dutch study') in which nursing sessions with older cancer patients (aged 65 years or older) in preparation for chemotherapy treatment were videotaped and analyzed (Chapter 4, 5, 6). These Chapters describe analyses conducted on data collected as part of a larger study investigating the effects of a communication skills training for oncology nurses on patient outcomes (Appendix 1). After a pre-test, hospitals that participated in the study were randomized to receive the training. As part of this training,

nurses practised addressing the emotional and informational needs of older patients. In this thesis, patients from the experimental hospitals at post-test were excluded as the training may have confounded the results. The varying number of participants is explained in Figure 1.

Recall in older cancer patients: measuring memory for medical information

In Chapter 4 we developed a questionnaire to measure older cancer patients' recall of information after a patient education session, conducted by nurses preceding chemotherapy treatment (Chapter 1, Figure 1.1, 4). Since our study was the first to investigate recall of this type of consultation (i.e. relatively long nursing encounters with older cancer patients), no existing questionnaire was available that suited the aims of our research. The recall questionnaire consisted of multiple-choice questions, completion items, and open-ended questions related to information about treatment and recommendations on how to manage side effects. Content validity of the questionnaire was tested by experts and checked with the responses from 10 older patients who had just been educated about chemotherapy treatment. Immediately after the nursing consultation older patients completed the questionnaire and recall was checked against the actual communication documented in video recordings. The results showed that, on average, 82 items were discussed during the consultations. The mean percentage of correctly recalled information was 23% for open-ended questions, 68% for completion items, and 80% for multiple-choice questions. Older cancer patients were thus confronted with a large amount of detailed information and recommendations and had marked difficulties actively recalling the information, whereas recognition memory was relatively good.

Emotional and informational patient cues: the impact of nurses' responses on recall

Sensitive responses to cancer patients' emotions and needs for information (labelled 'cues') have been associated with improved outcome such as reduced distress and increased patient satisfaction. We looked at these responses in relation to recall in Chapter 5 (Chapter 1, Figure 1.1, 5a-5c). From the theoretical framework it can be argued that clinicians' responses are even

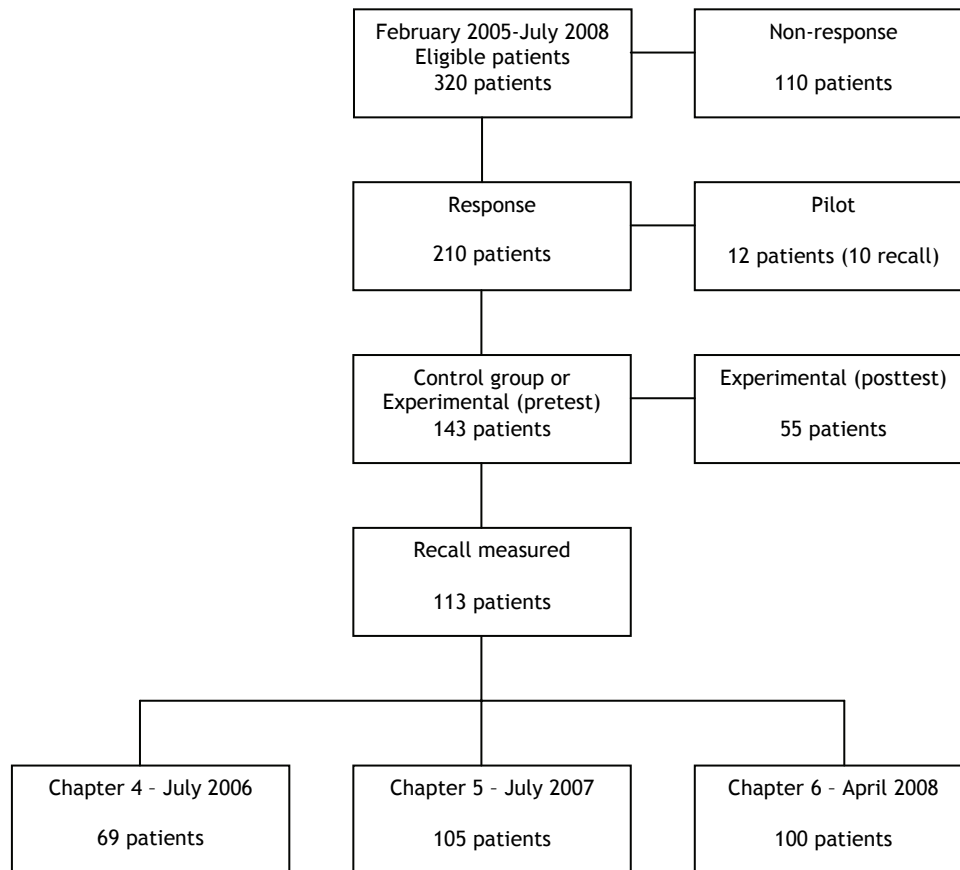
more important for older cancer patients, as they are less likely than younger patients to express their needs and worries, and are more likely to benefit from information that is attuned to their needs. We expected that if nurses endorse patients' cues, patients will remember more from the consultation. The cues and responses were coded using an adapted version of the Medical Interview Aural Rating Scale (MIARS). We found that the expression of neither emotional cues nor informational cues influenced recall. The way in which nurses responded to informational cues did not influence recall either, perhaps because there was only a slight variation in nurses' responses. In contrast, recall was affected by responses to the emotional cues of the patients. First of all, when nurses used minimal encouragements, such as "Hmmm" or "Go on" or functional silence, in response to an emotional cue, patients remembered more. Second, distancing responses, such as ignoring the cue or switching the focus away from the cue, resulted in lower recall scores.

The role of companions in aiding older cancer patients to recall medical information

As Chapter 3 showed, older cancer patients seem to have to some extent more difficulties recalling the information presented to them in the consultation than younger patients. Older cancer patients are more commonly accompanied to the consultation by family or friends. These companions may compensate for cognitive declines in older cancer patients by enhancing communication and thereby increasing recall. Furthermore, companions may remember different information and recall in the couple may be higher than recall in the patient alone. In Chapter 6 we investigated recall of information in unaccompanied and accompanied older cancer patients and their companions (6a-6c, Chapter 1, Figure 1). Patients completed measures of anxiety and memory-related beliefs, in addition to the recall questionnaire. Confirming our expectations, the results revealed that pooled recall in patient and companion couples was higher than their separate recall scores, both relative to the information presented and as an absolute measure. This clearly indicates that the older cancer patient and their companion supplement each other. Combined recall in the patient-companion dyad was also significantly higher than recall in unaccompanied patients for absolute scores but not for proportion of information recalled. Patients' beliefs about their own memory

performance predicted the recall scores of their companions rather than their own recall score. Nurses discussed more information when companions were present and accompanied consultations were longer in duration.

Figure 7.1 Patients included in the Dutch study (Chapters 3, 5 and 6)



General discussion

Now that we have provided an overview of the main results of the studies comprising this thesis, we would like to discuss the main findings in an integrative way. This general discussion will first be framed by an overview of the broad conceptual considerations that governed this research, followed by a deeper discussion of age differences in communication and information recall as regards patient-clinician consultations in oncology. We will also take this opportunity to discuss some of the methodological considerations that are relevant for this research, including the generalisability of the approach, and issues of study design and measurement. Finally, the discussion will be concluded by outlining some of the implications of these studies for oncology practice, and putting forward recommendations for future research in this area.

This thesis has highlighted communication with older cancer patients as a significant topic, as older men and women are disproportionately affected by cancer. Despite these demographics, remarkably little attention has been given to the specific issues of older cancer patients, although we are now beginning to see changes. This thesis has focused specifically on one outcome of patient-clinician communication, namely patient recall of information. It has been suggested that patients are more likely to adhere to their treatment if they remember treatment recommendations. As the chances of cognitive decline increase with age, this issue is especially relevant for older cancer patients. A better understanding of communication with older cancer patients and the ways in which age affects recall is critical for providing high quality of care for this patient group.

Age differences in communication and recall

We will first address the main topic of this thesis, i.e. how age influences communication between cancer patients and their clinician and patients' recall. In general, the relation between age, communication, and recall seems rather complex. Chapter 3 showed that older cancer patients remembered less, but this effect was only present when the amount of information presented and consultation length were controlled for. Furthermore, older

patients asked fewer questions compared with younger patients. In terms of the SOC (Baltes, 1997) model, older cancer patients, as well as their oncologist, may have attempted to compensate for age-related declines in the patient's resources; the patient by asking fewer questions, and the oncologist by presenting less information. This assumption is supported by previous studies relating patient age to reduced patient participation and a decrease in the amount of information delivered by the clinician (Eggle et al., 2006; Leigh, Gattellari, Butow, Brown, & Tattersall, 2001). Question asking was negatively associated with recall of information but this effect was fully explained in terms of the negative relation between amounts of information presented and recall. In support of this notion, previous studies have shown that more questions being asked leads directly to the provision of more information (Cegala, McClure, Marinelli, & Post, 2000; Street, 1991).

As outlined in the introduction, not all previous studies found age differences in cancer patients' recall. One of the reasons for the discrepancies may lie in the fact that significant predictors of recall can change depending on other variables included in the analysis. As this thesis shows, the amount of information provided is an important factor to take into account. This may also explain why most experimental studies do find age-differences in memory for medical information (Brown & Park, 2003), as in these studies the amount of information is generally held constant. Additionally, lower anxiety in older patients may have compensated for problems with information processing and may have advantaged them over younger patients. It must, however, be noted that anxiety did not directly influence recall in any of our studies. This issue will be discussed more extensively below.

Based on the SOC model (Baltes, 1997) and the theory of Socioemotional Selectivity (Carstensen, Isaacowitz, & Charles, 1999), we expected that, in an attempt to deal with reductions in physical and cognitive resources, older cancer patients would be more selective in their goals and needs. Moreover, we expected to find different needs, as older people may hold different beliefs about cancer, experience less conflict in roles, and are more familiar with illnesses. The current results only partially supported this notion. Overall, we found that age differences in patient needs for information and support were small. Older cancer patients prefer their clinician to give them a global picture

rather than detailed information regarding treatment for their illness and are less interested in information about issues related to sexuality and had lower needs for psychosocial support (Chapter 2). These findings, however, are not confirmed by the Australian study (Chapter 3) in which no age differences in information needs were found. When the current research started, only a handful of studies in the literature were designed to investigate the specific needs of older cancer patients, but this has now changed. Recent studies report age differences in needs, but in line with our findings, these differences are generally small (Giacalone et al., 2007; van Weert et al., submitted). It is therefore important that clinicians do not stereotype older cancer patients by assuming that they do not want complete information. An alternate argument is that the currently used need questionnaires are not sensitive enough to measure differences in those issues that are more relevant to older patients. More research is needed, perhaps using different ways of measuring needs, for example by looking at cancer patients' reasons for not wanting information (Zandbelt, 2008).

In conjunction with the findings that age-related differences were on average small to moderate, other factors were found to be equally important as age. This fits with the growing body of geriatric oncology literature suggesting that not chronological age per se but other factors, including poorer health and physical and psychological frailty, are important predictors of disease and treatment outcomes. Chapter 3 showed that patients with a worse prognosis, as estimated by the oncologist, remembered less of the information provided than patients with a better prognosis. It is unclear why and how patient prognosis is related to recall. Speculatively, patients with a poorer prognosis may block out and forget information because it is threatening, as a psychological defence mechanism to maintain hope and prevent getting more distressed (Gattellari, Butow, Tattersall, Dunn, & MacLeod, 1999; Myers & Derakshan, 2004; Vos & de Haes, 2007). This is supported by the notion that patients with a poorer prognosis are less likely to desire complete information about their illness (de Haes, 2006).

Also, the more doctors talked about prognosis, the less the patients recollected of the consultation (Chapter 3). This effect was unrelated to the actual prognosis of the patient. In the communication literature it is commonly

assumed that patients absorb little information after receiving bad news (e.g. Jefford & Tattersall, 2002; Ptacek & Eberhardt, 1996) and cancer patients often report that the distress they experience limits their ability to concentrate on the information in the consultation (Friis, Elverdam, & Schmidt, 2003; Harden et al., 2002; McJannett, Butow, Tattersall, & Thompson, 2003). However, there is little evidence of the impact of prognostic information on patient outcomes (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005). Our study is one of the first to provide empirical support for the anecdotal reports. Based on our results, we cannot pinpoint the underlying mechanisms, but other studies and psychological theories may provide insight into possible explanations. Irrespective of whether the received prognostic was 'good' or 'bad', how the patients perceived the prognosis might still affect their ability to concentrate on subsequent information. As such, a well-known psychological mechanism, i.e. attentional narrowing, may be involved (Christianson, 1992; Easterbrook, 1959; Kessels, 2003; Wessel, van der Kooy, & Merckelbach, 2000). When patients encounter stressful information (e.g. prognostic information) this can become the centre of their attention at the cost of other, more peripheral information (e.g. treatment related information). This would suggest that patients remember information regarding their prognosis better than other information, more research is needed to establish if this is indeed the case.

Surprisingly, the effects of both the doctors' estimation of the patient's prognosis and the discussion of prognostic information on recall could not be explained in terms of the patient's anxiety. Moreover, anxiety was not associated with recall in any of our studies. Anxiety is the emotion most commonly expressed by cancer patients and the most often used measure of distress in psychological studies (Anderson et al., 2008; Hanoch & Vitouch, 2004). However, empirical findings are mixed in regards to the effect of patient anxiety on recall of medical information. Some have reported a curvilinear or inverted U shape relationship between emotional distress and recall, with both low and high levels of anxiety decreasing performance (Ley, 1988; Pickersgill & Owen, 1992). Others reported a positive relation between anxiety and recall (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999; Ley, 1988). Finally, some studies did not find any effects of anxiety on cancer patient's information recall (Leighl et al., 2001). According to Hanoch &

Vitouch (2004), the fact that emotional arousal (i.e. emotional distress) affects attention and restricts the amount of information processed may help people in complex situations to focus more on the essential information. To a certain extent, emotional distress may therefore help patients to focus on the information that is most important to them. In our study, we did not categorize information according to their level of importance, but this might be interesting to investigate in future studies.

Altogether, this thesis supports the assumption that although aging is associated with declines, these changes are multidimensional and result in small but marked age differences in communication and recall. We found the patients' prognosis has a robust effect on recall, in line with other studies that suggest that vulnerability rather than chronological age is an important factor in clinician-patient communication and recall.

Cancer patients retain little of the information presented to them, regardless of age

Apart from the factors influencing the amount of information recalled by older cancer patients, a general finding of our studies is that, regardless of age, cancer patients do not remember much information after a consultation with their doctor or nurse. Cancer patients recalled less than 50% of the information from their initial consultation with an oncologist (Chapter 3), and less than 25% of the information provided during pre-chemotherapy educational sessions with a nurse (Chapter 4-6). Differences in, for example, patient sample, type and length of consultation as well as recall measurement and time of assessment preclude a direct comparison between these scores, but the message is essentially the same. Previous studies have reported similar low recall scores, suggesting that cancer patients may often not be in the right frame of mind to absorb large amounts of information (Brown, Butow, Dunn, & Tattersall, 2001; Butow, Brindle, McConnell, Boakes, & Tattersall, 1998; Dunn, Steginga, Rose, Scott, & Allison, 2004; Gabrijel et al., 2008; Gattellari et al., 1999; Olver, Turrell, Olszewski, & Willson, 1995). As a patient in our study wrote in response to one of the recall questions, *"I really can't remember.. when I was told I have cancer I was confronted with so many different things and it felt like the world had collapsed"*.

Older cancer patients were relatively good at recognizing information, as indicated by the higher scores on multiple-choice questions and completion-items compared with open-ended questions (Chapter 3). Theories on aging suggest that, as people get older, they have more difficulties with cognitive processes that take effort, whereas more automatic processes are relatively preserved (Brown & Park, 2003; Hess, 2005). Patients may thus be able to recognize side effects of their treatment the moment they occur, but have difficulties remembering information about preventive measures, as these have to be remembered without external cues. Generally speaking, side effects of chemotherapy treatment are easier to prevent than to treat, but this requires patients to actively remember which precautions to take. Taken together, this suggests that in their education clinicians should focus especially on those side effects that can be prevented by the patient.

As said above, one of the reasons patients retained so little is that they are confronted with large amounts of information in the consultations. This is underscored by the fact that in all our studies, the amount of information presented was a significant predictor of recall. However, it is important to note that the direction of prediction was negative for proportion recall and positive for absolute scores. That is, a patient who is given more information about their disease is likely to know more and recall more, but may remember proportionally less (Ley, 1988; Rost & Roter, 1987; Roter, Hall, & Katz, 1987). The consultations in the Dutch study were much longer than the Australian study and much more information was presented. Nevertheless, the average number of items that older patients recalled was remarkably similar, i.e. eight in the former and six in the latter. It is tempting to link these findings with George Miller's famous paper (1956) 'the magical number 7', indicating a limitation in the amount of information cancer patients can effectively process. According to Miller, when the amount of information is increased, the recalled information will increase at first but it will eventually level off at some asymptotic value. Indeed, the non-linear relation found between the amount of information presented and percentage information recall (Chapter 3, 6) supports such a notion. Evidently, patients need to remember the information that is most important from their perspective or the clinicians' perspective (Michie, French, Allanson, Bobrow, & Marteau, 1997). They do not necessarily have to remember all the details of the consultation. Focusing on

the main message rather than details may be an adaptive strategy when all information cannot be recalled, especially for older patients (Gould, Osborn, Krein, & Mortenson, 2002). More detailed, qualitative analysis are required to shed more light on the level of information patients need to recall in order to make informed treatment decisions and manage side-effects at home and the relation between the relevance of the information and recall.

Information giving in oncology

Older patients thus have difficulty remembering the information they are presented with in cancer consultations, but some issues might be considered to provide information more effectively in oncology settings.

It is challenging to determine the appropriate type and amount of information to impart to cancer patients. Information can give people a sense of control, but for others too much information is overwhelming. In this thesis, we found only small age differences in information needs. This means that inferring patient preferences from their age is likely not to be accurate and other factors should be used to present information more flexibly and attuned to the individual patient (Jenkins, Fallowfield, & Saul, 2001; Pinquart & Duberstein, 2004). The Dutch study indicated that nurses generally follow the information in the ‘Treatment Guide to Chemotherapy’, a booklet that many hospitals in the Netherlands give to patients who undergo chemotherapy. This is an excellent source of information for patients; however, it was not developed with the intention to use it as a communication tool. As a relative of a patient in one of the focus groups of the larger study stated *“My experience is that during patient education, no distinction was made between different patients. For example, we didn’t feel like talking about getting in contact with other patients, but the nurse kept talking about this. The conversation was led by preset ideas the nurse had in mind and she didn’t ask us: ‘Is it all clear?’ or ‘What kind of information would you like?’ It was like she had to stick to her mission”* (Posma, van Weert, Jansen, & Bensing, 2009). This is an example of the friction that may exist between giving general but evidence-based information and patient preferences. In cancer care, a patient centred approach is now generally advocated (Arora, 2008; Epstein & Street, 2007). Patient-centred information giving encompasses asking patients about their

information needs, providing patients with sufficient information that is clear and understandable for the patient, timely, and last but not least, tailored to the needs and situation of each individual patient (Epstein & Street, 2007). According to this definition, patient-centred communication may sometimes mean not giving all information or not giving it all at one particular point in time (see also de Haes, 2006).

Socio-emotional communication and the presence of a companion aid recall in older cancer patients

So far, we have mainly described factors that have a negative impact on older cancer patients' recall. Fortunately, our results also showed aspects of communication that potentially improve recall in these patients.

To start, the way nurses respond to expressions of emotions (i.e. emotional cues) influenced how much older cancer patients remembered from the session (Chapter 5). More specifically, distancing responses such as ignoring the cue or switching the focus away from the cue had a negative effect whereas minimal encouragements like 'hmmm' or functional silence had a positive effect. In the theoretical framework, it was outlined that emotions become more salient with age and that integrating information in an emotional context makes information more meaningful for older people and easier to process (Hanoch, Wood, & Rice, 2007; Hess, 2005). We did not compare older and younger patients in this study, but the results provide some evidence for this notion.

Although nurses do not actively endorse the patients' emotions by giving minimal encouragers, these responses are likely to give the patients a feeling that the nurse is listening to them. This increases the chance of two-way interaction in which nurses are better equipped to attune the information to the older patients needs and emotions (Mauksch, Dugdale, Dodson, & Epstein, 2008; Neumann et al., 2007). Health professionals are often uncomfortable with responding to and eliciting patients' emotions and, as in our study, often respond to emotions by giving information or other distancing responses (De Valck, Bruynooghe, Bensing, Kerssens, & Hulsman, 2001; Heaven et al., 2006; Uitterhoeve et al., 2007; Zimmermann, Del Piccolo, & Finset, 2007). Our study hints at the importance of responding to a patient's emotional cues, as it is

likely to enhance recall. Even unobtrusive responses, such as minimal encouragers, are sufficient to have a beneficial effect. A few words of caution are in order. Firstly, the results regarding distancing responses need to be interpreted with care, as their reliability was low. Secondly, although we looked at the sequence of patient cue to nurse response, we did not analyze the importance of the cue within the context of the consultation. For the patient, it may be more important that some cues are met than others. Moreover, not all cues may require the same response; this may depend on the content and the intensity of the emotion. We were not able to investigate these issues in the current study, but it would be worthwhile to do so in the future.

Previous studies have shown that companions can be a great source of support, especially for cancer patients or patients who are older. Furthermore, companions may facilitate communication between patient and clinician (Clayman, Roter, Wisow, & Bandeen-Roche, 2005; Ishikawa, Roter, Yamazaki, & Takayama, 2005; Street & Gordon, 2008; Wolff & Roter, 2008). To quote a nurse who participated in one of the focus groups we held as part of the larger study *“I think children often ask very relevant questions during the consultation, something the father or mother did not think about. Patients often tell more when somebody they know is present. As a nurse, you receive more complete information, like: ‘Well mum, you did not yet tell, that...’*” (Posma et al., 2009). Our studies suggest that it is important to have a triadic rather than dyadic view on communication in cancer care, as companion-patient couples remembered more together than either one alone (Chapter 6). However, this does not necessarily mean that the presence of a companion always had beneficial effects on recall. In absolute terms, unaccompanied patients recalled roughly the same amount of information as accompanied patients, and proportionally they even remembered slightly more. Also, recall in companion and patient was interlinked. Depending on characteristics of the patients (i.e. beliefs about their memory performance), companions recalled more or less themselves.

Of course there are reasons other than improving recall for bringing a companion to the consultation such as providing emotional support and companionship, aid in decision-making, and assisting in interpreting

information (Beisecker, 1994; Clayman et al., 2005; Ellingson, 2002; Glasser, Prohaska, & Gravdal, 2001; Schilling et al., 2002). Some have criticized accompanied visits because they claim that companions take away the attention a medical provider would usually give directly to the patient (Beisecker, 1989; Greene, Majerovitz, Adelman, & Rizzo, 1994). This has been opposed by a recent survey by Wolff et al. (2008) showing that accompanied patients were more satisfied with the communication and care provided by their physician than unaccompanied patients. Altogether, the presence of a companion can be an important compensation mechanism for older cancer patients to deal with a decline in resources, but is not a guarantee that more will be remembered.

Methodological considerations

We thus far described the results of our studies and will now address some methodological strengths and weaknesses that are worth mentioning. The main focus will be on the Dutch study, as it formed the backbone of this thesis. First, some general methodological considerations will be discussed, followed by the generalisability of the approach, and issues of study design and measurement.

General considerations

As mentioned before, the older population of cancer patients has been largely neglected in clinical as well as psychosocial research until recently. Our study was one of the first to explore the specific issues associated with communication and the older cancer patient. Furthermore, the complex dynamics of the clinician- companion- patient interaction thus far have received little attention.

The use of video-observations allowed us to take non-verbal as well as verbal aspects into account when coding the communication content of the consultation. This was especially helpful when coding patients' emotional and informational cues with the MIARS. The videotapes also provided a means to compare the facts that patients recalled against the actual information presented in the consultation, this is a laborious but more reliable method

than using physician report or medical records to verify patients responses (Michie et al., 1997). Indeed, this method resulted in a highly reliable recall measure with a mean Cohen's Kappa ranging from 0.77 for the multiple choice questions to 0.97 for the open-ended questions.

In addition, novel approaches were used to analysing the resulting data. To assess the effect of companions and patients on information recall, the Actor-Partner Interdependence Model (APIM) was used. This method allowed assessment of the effect of patient and companion characteristics on their own recall scores, as well as the effect of their characteristics on their partner's recall scores (Kenny, 1996; Kenny, Mannetti, Pierro, Livi, & Kashy, 2002). We looked at cues and responses using sequence analysis, which is a relatively new approach to studying communication in health care. Sequence analysis is appropriate to analyse rare events that would otherwise be overshadowed by more common aspects of the consultation, and avoids some of the chicken-egg issues associated with correlational studies (Eide, Quera, Graugaard, & Finset, 2004; Zimmermann et al., 2007). It therefore allows a more precise analysis of the patient-clinician dynamics in the consultation.

Both studies described in this thesis were complex and therefore have some limitations. Firstly, the multicentre character of the Dutch study made the logistics rather complex. 135 nurses from ten different hospitals in several locations in The Netherlands participated in this study. In each hospital, patient education about chemotherapy treatment was organized differently. Often, the educational sessions were scheduled ad hoc, with little time between the consultation with the oncologist in which the treatment decision was made, the educational session with the nurse, and the actual start of the chemotherapy treatment. Therefore, patients had little time (maximum of a few days) to decide about participation and we could not collect any data before the consultation. In some hospitals, the nurse was only able to invite the patient to participate just before the educational session. In other hospitals, patients received their first treatment just after their educational session, which complicated the completion of questionnaires.

Furthermore, the study involved videotaping the consultation with an unmanned camera and required a researcher to be present to set up the

camera for each patient. The presence of a camera may have influenced patients' willingness to participate. Indeed, 21 (of the 320) patients reported that they did not want to participate, as they were afraid the presence of a camera would hold them back in asking questions and expressing their emotions.

The overriding reason for the complexity of this study is the difficulty of conducting research with a vulnerable patient group such as cancer patients, especially when they are older (Chouliara, Kearney, Worth, & Stott, 2004). The patients had recently learned that they had cancer or that a previously diagnosed cancer had recurred or spread. Also, there were often one or more companions present, and sometimes the patient did wish to participate but their companion refused. In light of these issues, the response rate in our study (66% for the larger study) was relatively high. To compare, a two-centre study of audiotaped visits between older patients and their general physician had a response rate of 58% (Shields et al., 2005). The larger study showed that overall the participating patients were younger than non-participating patients but did not differ in gender.

Generalisability and external validity

Can the results of our study be generalised to other settings and patient populations? Our study was conducted in two patient samples, one with Australian cancer patients of all ages, and one with Dutch cancer patients aged 65 years or older. Both populations included patients with various cancer diagnoses, hence reflecting the diversity in regular outpatient oncology departments. The sample size of the Dutch study was small (range: 69 Chapter 3-105 in Chapter 5), but despite that, we were able to identify relevant factors that significantly influenced information recall in older cancer patients. Differences in the Dutch and Australian health care system, as well as cultural differences and differences in the curriculum for medical students may influence the content and style of the clinical communication (De Valck, Bensing, Bruynooghe, & Batenburg, 2001; van den Brink-Muinen et al., 2003). It is therefore unclear if the results of the Australian study can be directly extrapolated to the Dutch situation. Doctors and nurses have different roles in communicating with cancer patients, and may exhibit different communication

styles (Collins, 2005; Uitterhoeve, Duijnhouwer, Ambaum, & van Achterberg, 2003). As a result, we may not be able to generalize the results of the nurse-patient study to doctor-patient communication and vice versa. As the consultations in this thesis were recorded, there is always the risk that nurses and doctors behaved differently than in a normal, unmonitored consultation. Others have previously addressed this and concluded that these concerns do not limit the validity or the reliability of results (Caris-Verhallen, 1999; Timmermans, 2007; van Weert, van Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005). To add, most of the nurses in the Dutch study reported in a questionnaire afterwards that the videotaped encounter reflected the normal situation. Furthermore, the nurses from the different outpatient clinics participated in the study as part of their regular employment duties. When an eligible patient was identified, the nurse who was scheduled to give patient education participated in the study so that the normal routine was maintained as much as possible.

Study design

Our aim was to study patient-clinician communication in a first outpatient visit, either the first educational session with a nurse about chemotherapy treatment, or the first consultation with a medical or radiation oncologist. We measured recall after the consultation, this way the determinants of information recall could be studied. One may, however, argue that the assessment of factors that influence recall would require experimental research methods (Fogarty et al., 1999; Schmid Mast, Kindlimann, & Langewitz, 2005). To disentangle the effects of the patients' prognosis and emotions versus the providers' communication (Chapter 4, 5) an experimental design in which each of these factors is systematically varied while the other factors remain fixed would be ideal. Similarly in Chapter 6, a study design in which patients are randomly allocated to bring a companion or not is necessary to unravel whether the recall effects are a result of being accompanied or the effect of patient characteristics associated with preference for being accompanied (Shields et al., 2005).

In the studies reported in this thesis, the patient-clinician encounters involved different nurses (Chapter 4, 5, 6) and different doctors (Chapter 3).

Inconsistencies and variability may exist in the quality of delivery of the information across clinicians because of their communication style. It might therefore be argued that encounters with the same clinician are more similar than those with different clinicians (Hox, 1995). If the data allowed us to, we controlled for clustering in the analyses.

Measurements

We included patients in our study if they were 65 years or older. This is an arbitrary cut-off, despite being commonly used in geriatric oncology (Aapro & Johnson, 2007) and the use of this definition of older patients may be challenged. Following a definition of 'older' as those of age 65 or greater means including all members of the population aged between 65 and 100, or even older. This is clearly a broad and mixed group of individuals. Therefore, some researchers divide the older patient population into two or three different cohorts (Adelman, Greene, & Ory, 2000). For example, Baltes (1997) makes the distinction between the young-old, (60-80 years old), and the oldest-old (80-100 years old). The oldest old experience more universal decline and are at much higher risk for frailty and other reductions in general function than the young-old. These different age groups may also have unique emotional and social issues (Harden, 2005). In our studies, only few eligible patients were identified who were 80 years or older, suggesting that chemotherapy and radiotherapy treatment in these patients is rare.

Our studies did not allow including objective measurements of patients' sensory deficits or cognitive function. Nevertheless, patients with non age-related cognitive impairments (according to their medical record) were excluded; rendering it unlikely that patients with clear cognitive deficits such as dementia participated. We did measure cognitive functioning in a sub sample of 30 patients, using the Dutch version of the Telephone Interview for Cognitive Status (Kempen, Meier, Bouwens, van Deursen, & Verhey, 2007), showing that none of the patients of this sample (except one patient who scored just one point below cut-off) fulfilled the criteria for cognitive impairment. Since more than half of the patients in Chapter 6 reported memory complaints, it is very likely that patients may have had more subtle, age-related cognitive deficits.

It is important that the seemingly low recall rates obtained in the Dutch study are interpreted in the context of the scoring system that we used. An information item was defined as a segment of speech expressing a single idea concerning treatment and disease related issues (Dunn et al., 1993). The observation checklist therefore covered the specific items of the consultation very precisely and a one on one comparison was made between the items presented and recalled. At no point were items selected a priori to be of greater importance. Furthermore, recall was measured using a recall questionnaire. This means that we did not probe recall, i.e. continue to ask questions until satisfied that the patient was unable to recall any more information (Silberman, Tentler, Ramgopal, & Epstein, 2008). Should such a procedure be used to test recall it is entirely consistent that it will increase the observed recall rate from what we found using the questionnaire alone.

Implications for practice

Thus far we have summarized the main findings of our studies, discussed them in the context of relevant literature, and described methodological considerations. Next, we will outline some of the implications of these studies for oncology practice.

Be aware of older patients' issues but avoid stereotypes

The results of our studies confirm that patients' preferences cannot easily be predicted based on their chronological age (Chapter 2, 3). As many others have suggested before, clinicians may have to ask their patients directly for their information needs and preferences rather than base their judgment simply on the patient's age or other background characteristics. Clinicians could for example ask patients *"some people want lots of details, some want the big picture, what would be best for you?"* (Back & Arnold, 2006b). Alternatively, clinicians could ask more explicitly whether the patient wants to be informed about all possible side effects or just the most common/most severe side effects, about the expected effect of therapy (e.g. the chance to be cured), if and how long he or she would have to stay in the hospital, etcetera (see also Pinqart & Duberstein, 2004). Asking patients what information they want

seems to be especially important in relation to prognostic information (Back & Arnold, 2006a, 2006b; Clayton et al., 2007; Franssen et al., in Press).

Balance information with responding to emotions

It is important to communicate information in a way that is responsive to subtle cues of the patient's emotions (Chapter 5). In particular, clinicians should be aware of the effect that information about prognosis has on the patient as it may limit their ability to process important information discussed in the consultation (Chapter 3). Sometimes the clinician may have to decide to spend more time in that particular consultation offering reassurance or support and discuss the rest of the information in a subsequent consultation (Back & Arnold, 2006b; Epstein & Street, 2007; Mauksch et al., 2008). However, this should be negotiated with the patient, as not all patients may prefer scheduling a new, separate appointment (Posma et al., 2009).

The role of companions

Accompanied patients are likely to benefit from the extra information that their companions remember (Chapter 6). At the same time, our study showed that companions increase the length of consultations and patients who attend the consultation alone recall at least as much as accompanied patients. Altogether, it is recommended that clinicians accommodate the patients' preferences for accompaniment rather than encouraging all patients to bring a companion.

Recall promoting behaviours

Although clinicians must find equilibrium between enhancing recall and the risk of sounding condescending, some behaviours have been suggested to make information more memorable for (older) cancer patients (Ley, 1988; Silberman et al., 2008; Snelgrove, 2006). Being selective in the information one wishes to discuss and prioritizing the most important, personally relevant information is one of these. More specifically, in pre-chemotherapy education sessions, clinicians should focus especially on those side effects that can be prevented by the patient (Chapter 3). Others include providing information in a structured, categorized manner, detect possible sensory deficits and

compensate for these, and minimize distractions. Clinicians should sit face to face with the patient and maintain eye contact, speak slowly, clearly and loudly and avoid the use of jargon. Summarizing and repeating the most important information is suggested, encouraging the patient to take notes, and giving information at different time points. To conclude, a good approach may be to ask patients for their active recall at the end of the consultation, for example *“Could you tell me what you are taking away from this conversation today?”* (Back & Arnold, 2006a).

What older cancer patients recall can be controlled to some extent by use of these techniques, but we expect that overall, information recall in cancer patients will remain low. Providing patients with an audiotape of their consultations seems to be particularly effective in increasing recall, although a recent study showed that patients might not want an audiotape of the discussion about their prognosis (Lagarde et al., 2008). Appendix B gives an overview of interventions, such as audiotapes and question prompt lists, designed to improve recall in cancer patients (van der Meulen, Jansen, van Dulmen, Bensing, & van Weert, 2008).

Attune patient education to older patients needs

As previously mentioned, effective patient education involves giving information that is specifically adapted for individual patients rather than giving general information. This avoids irrelevant and potentially confusing details, and may especially improve recall in the older patient (Dunn et al., 1993; Morrow et al., 2005). It is important, however, to note that organizational aspects may complicate tailored patient education, especially for nurses.

A first prerequisite for tailoring information is knowledge of the individual patient’s characteristics. It is therefore imperative that nurses have information about the patient’s background before the consultation (e.g. history of the illness, complications, social background). Based on that information they can signal possible areas of difficulties during the consultation and ask the patient targeted questions. This approach has the added advantage that patients do not have to tell the same story every time

again. However, in our study, nurses did not always have access to the patient's medical file. Older cancer patients usually receive care from multiple professionals. To work effectively in a multidisciplinary team, sharing information about patients is essential. Secondly, in addition to general booklets such as the Dutch 'Treatment Guide to Chemotherapy', nurses need more specific information about the treatment regimen the patient is about to receive, e.g. the length and number of treatments, the specific side effects for that treatment. Although not reported in any of our papers, we know from our study that this information is not always provided. Thirdly, as previously mentioned, it is important to educate older patients in a quiet environment without any distractions. While doctors have a consultation room, nurses do not necessarily have a dedicated space to give their education. Finally, patient education is one of many aspects of the work of oncology nurses. Often, they have to interchange bedside care or activities related to the administration of chemotherapy in outpatient clinics, with the occasional patient educational session. Nurses should have enough time to prepare for the educational session, read the patients' medical file, set their agenda for the consultation and prioritize the information they want to give.

Recommendations for future research

Finally, we would like to put forward some recommendations for future research in this area. As studies have suggested before, this thesis shows that cancer patients forget a substantial part of the information presented in the consultation. It is unlikely that anyone can accurately retain the large amounts of information that were presented in the consultation completely. More detailed, qualitative analysis is necessary to establish if the information that patients remember is indeed the most important information (from both patient and clinician perspective) to help them make informed decisions and manage side effects at home.

In this thesis, the aim was to establish the effect of age and age-related factors on communication and recall. A wide range of patient factors was included, but the studies were by no means exhaustive. Future studies on recall of information in older cancer patients could benefit from taking into

account the patient's (health) literacy (Ley, 1988), cognitive function (Insel, Morrow, Brewer, & Figueredo, 2006) sensory function (Hess, 2005) and/or results of a comprehensive geriatric assessment (Extermann & Hurria, 2007).

We depicted aspects of communication that may enhance older cancer patients' recall. Additional studies are needed to determine which of these can be feasibly applied in communication in cancer care to promote recall.

This thesis sheds some light on the communication features of companions in encounters and how they may aid older cancer patients in remembering information. Clearly, more research is needed to understand the complex dynamics of clinician-patient-companion(s) communication and how each of the communicative participants can function to improve outcomes for patients as well as their families.

A surprising result was that although prognosis and prognostic information negatively influenced recall, recall was not related to anxiety. To disentangle the complex interaction between prognosis, emotions, information and recall, future studies should use additional measurements of distress. For example by investigating the effects of more specific types of anxiety such as fear of recurrence (Franssen et al., in Press) or using implicit, physiological measures of distress such as heart rate, blood pressure and skin conductance. To add, more insight could be gained by investigating cognitive strategies such as denial (Vos & de Haes, 2007) or coping style (Myers & Derakshan, 2004; van Zuuren, de Groot, Mulder, & Muris, 1996).

Further developments

As outlined in Chapter 1, this thesis was part of a larger study aimed at improving treatment related patient education in older cancer patients (van Weert et al., 2008a; 2008b; www.nivel.nl/voice). The results of the studies described in this thesis, together with other findings, resulted recommendations that can be summarized as follows:

1. Set priorities and structure the information presented
2. Tailor information to the individual older patient's situation and needs
3. Address the patient's emotions

Based on these recommendations, we developed an intervention in collaboration with The Netherlands Cancer Institute (NKI-AVL); the results of the outcomes of this intervention are pending. Please refer to Appendix A for a more detailed description of the overarching study.

Concluding remarks

This thesis showed that cancer patients generally retain little of the information presented in the consultation, especially older cancer patients and patients with a worse prognosis. Patients were confronted with a lot of detailed information and recommendations and it can be expected that the amount of information available to patients will only increase in the future. William James (1890) was probably right: patients have to be selective in what they remember. It is the clinicians' task to ensure that patients remember the information that is most important to their specific situation. This involves helping patients and their families to express their needs and emotions and select information accordingly.

Appendix A

Overview of the overarching study

The overarching study aimed to investigate the extent to which the communication during nursing sessions preceding chemotherapy is attuned to older patients' needs and to improve treatment related patient education in older cancer patients (van Weert et al., 2008a; van Weert et al., 2008b; www.nivel.nl/voice). This study is a quasi-experimental pre-test post-test control group design (see Figure A.1).

Figure A.1 Design of the study

Phase 0	
Focus groups & interviews patients & relatives (Posma et al., 2009)	
Focus groups professionals (Posma et al., 2009)	
Literature review (Chapter 2)	
<hr/>	
Experimental group	Control group
6 outpatient departments involved in nursing education about chemotherapy treatment	6 outpatient departments involved in nursing education about chemotherapy treatment
<hr/>	
Pre-test	Pre-test
62 older cancer patients (aged 65 years or older)	51 older cancer patients (aged 65 years or older)
<hr/>	
Intervention	Intervention
<i>Nurses:</i>	Education as usual
Video-feedback	
Training	
Follow-up meeting	
<i>Patients:</i>	
QPS/booklet	
<hr/>	
Post-test	Post-test
55 older cancer patients (aged 65 years or older)	41 older cancer patients (aged 65 years or older)

Phase 0

At the start of the project, face-to-face interviews were undertaken in a sample of consecutive older cancer patients, who had received two cycles of chemotherapy. Patients were invited to talk about their expectations and experiences concerning chemotherapy. Interviews were undertaken until saturation (i.e. no new information on themes emerged). Five focus group meetings were conducted. Two meetings involved older cancer patients (and their partners) who had been treated with cancer in the past and three focus groups consisted of professionals with a background in oncology, gerontology, nursing care and/or patient-provider communication (Posma et al., 2009). Based on the focus group, interviews and the literature review described in **Chapter 2** of this thesis, we developed a 68 items questionnaire, QUOTE^{chemo}, in which specific needs and expectations of people receiving chemotherapy are evaluated (van Weert et al., submitted).

Pre-test

During Pre-test real nurse-patient encounters preparing the patient for chemotherapy treatment were videotaped. The encounters lasted on average 55 minutes. Directly after the nursing encounter, the patient, his or her companion and the nurse were asked to complete a questionnaire. In addition, data of patients were gathered by a second questionnaire and telephone interview, approximately 6 weeks after the first treatment. The main outcome measures were recall of information (see **Chapter 4**), fulfillment of patient' needs, satisfaction, self-efficacy and anxiety. Furthermore, data was gathered on disease-status, socio-demographics, quality of life, information preferences, information seeking behavior and social circumstances.

Recommendations

Based on the findings of the pre-test, recommendations were formulated. The main recommendations were to:

1. Set priorities and structure the information presented
2. Tailor information to the individual older patients' situation and needs
3. Address patients' emotions

Intervention

To implement these recommendations, we developed an intervention in collaboration with The Netherlands Cancer Institute (NKI-AVL). This intervention aimed at enhancing nurses' knowledge and skills regarding education about chemotherapy treatment for older cancer patients. It consisted of 1) one-to-one video-feedback, 2) a one-day training session, including role-play, 3) a follow-up meeting, 4) a patient booklet including a Question Prompt.

In preparation of the group training session, nurses received individual feedback on one of their videotaped encounters with older cancer patients. During the subsequent training session, a couple of weeks later, nurses were taught to structure their educational sessions differently and how to use the patient booklet in their consultation (see Figure A.2). The training furthermore involved role-play in which nurses practiced communication skills, with a specific focus on how to detect and respond to patients' emotions. During the follow-up session, nurses were further trained in communication skills. But the main goal of this meeting was to facilitate transfer of the newly acquired skills into practice and to discuss organizational changes that were needed to implement the new care model successfully. We also developed a booklet for patients that included an outline of the educational session and a Question Prompt Sheet (a structured list of questions that patients may want to ask their nurse).

Figure A.2 Proposed new structure of the consultation

Part 1 Introduction Information about chemotherapy and side-effects
Break
Part 2 Other information and issues brought up by patients during break Summary and conclusions

Post-test

During the second phase of the study (post-test) we evaluated the suitability of the recommendations. In order to have a randomised controlled trial, half of the nurses were randomised to receive the training. The other half served as a control group and had the intervention after the post-test measurement. Randomisation took place at outpatient department levels, to avoid contamination. The methods used at post-test were comparable to pre-test. The results of this study are pending.

Appendix B

Interventions to improve recall of medical information in cancer patients: a systematic review of the literature

Abstract

This systematic review investigates which interventions are effective to improve recall of medical information in cancer patients. A literature research was done in PubMed, PsychINFO, CINAHL and Cochrane Library, following the guidelines of the Cochrane Collaboration. The methodological quality of selected studies was assessed independently by two reviewers. The results were synthesized with a Best Evidence Synthesis. Of initially 5173 found publications, 10 met all selection criteria. The results indicate that an audiotape of the patients' own consultation has added value upon oral information only. However, providing patients with a general audiotape does not improve recall of information and might even inhibit patients' recall. Furthermore, there is scientific evidence, although limited, that the use of a question prompt sheet (QPS) has a positive effect on recall of information, provided that the physician actively endorses this sheet. No evidence was found for an effect of providing patients with a summary letter of the consultation on recall, although research on this subject is scarce. In conclusion, the review suggests that interventions that are tailored to the individual cancer patient, such as an audiotape of the consultation or a QPS, are most effective. Further research needs to be done to establish robust results.

Published as: van der Meulen, N., Jansen, J., van Dulmen, S., Bensing, J., & van Weert, J. (2008). Interventions to improve recall of medical information in cancer patients: a systematic review of the literature. *Psycho-Oncology*, 17(9), 857-868.

Introduction

One of health professionals' major tasks is to inform patients about the diagnosis, prognosis, treatment and side effects of treatment. The goal of providing such information is to prepare patients for their treatment, to increase adherence to therapy and abilities to cope with the illness and to promote recovery. Patients must understand and be able to recall medical information because accurate knowledge is likely to improve outcome (1,2) in terms of better compliance (3,2), higher patient satisfaction (2), more adequate disease management and decreased anxiety (4,5). Therefore, it is important to know what promotes recall of medical information by patients.

Recall in historical perspective

Studies on recall of medical information were conducted as early as the seventies and eighties. Anderson et al. (6) for example, showed that patients wrongly remembered more than half of the medical information given. Evidence regarding recall of information among various groups of patients was summarized by Ley (7,8). Heart surgery patients could not reproduce 71% of the received information. For rheumatic patients, this percentage varied between 52% and 69%. Outpatients with cancer forgot 31% of the received written information. Ley (8) distinguished communication techniques that might positively influence recall, e.g. simplification, explicit categorization, repetition and the use of specific rather than general recommendations. Kessels (2) presented the results of more recent research on recall of information. His overview showed that 40-80% of the medical information presented by healthcare professionals was forgotten immediately by patients. Kessels (2) explained this in terms of the use of difficult medical terminology, factors related to the patient, such as low education, and mode of information presentation.

Recall and cancer

During the last decades, a shift was observed from examining factors related to recall, to research into the effectiveness of interventions aiming to improve recall of information. The underlying assumption is that the provision of additional educational materials, complementary to oral information, might result in increased recall scores. Cancer patients need to recall important

information about their disease and treatment to be able to deal with the illness and side effects at home. It is important that health care professionals have knowledge about state-of-the-art methods to effectively educate these patients. To our knowledge, no recent review studied the effectiveness of different interventions on cancer patients' recall of information. Therefore a review study was set up to answer the following question:

What kinds of interventions are effective to improve recall of medical information provided to cancer patients?

Methods

This review followed the guidelines of the Cochrane Collaboration and summarizes the existing evidence about interventions in cancer care that could improve patients' recall of medical information. Recall was defined as the ability to reproduce the information provided about cancer and its treatment accurately and in detail.

Inclusion criteria

A study was included in the review if: a) it concerned a randomized controlled trial (RCT), a controlled clinical trial (CCT) or a randomized trial (RT), b) the study was published in Dutch or English, c) the study population consisted of patients with cancer who were given information about their diagnosis or treatment, d) the population of professionals consisted of doctors and/or nurses working in cancer care, e) one of the outcome measures was recall of information. According to Michie et al. (9) recall is only measured appropriately when it is compared with the information that was actually given. Therefore, (f) only studies that related the patients' reproduction of information to the information provided (e.g. analyzed against an audiotape of the consultation) were included. Furthermore, (g) studies had to be published between 1990 - jan 2007.

Search method

A computerized literature search was conducted to find intervention studies that fulfilled all seven inclusion criteria. Four databases were searched:

PubMed, PsychINFO, CINAHL and The Cochrane Library. The computerized search was build upon the following components: a) the search strategy for randomized trials (RCT,CCT, RT) and b) the search strategy for the identification of studies involving cancer patients and recall of information using the following keywords: (cancer OR neoplasms) AND patient AND (information OR patient education) AND (recall OR retention OR knowledge). Additionally, the reference lists of all relevant studies and reviews were scanned for potential articles (snowball method).

Selection method

A first selection for inclusion was performed by the first author (NvdM) based on titles and abstracts. Studies that did not meet one of the seven inclusion criteria were excluded from the review. If a study seemed to meet the inclusion criteria or in case of doubt, the full article was obtained. On the basis of the full articles two reviewers (NvdM, JvW) independently checked if the selected studies satisfied all seven criteria. Disagreements were resolved by discussion and if agreement could not be achieved a third reviewer (JJ) was consulted.

Assessment of methodological quality

The methodological quality of the RCT's and CCT's was independently assessed by two reviewers (NvdM and JJ) using the list from the Cochrane Collaboration Back Review Group by Van Tulder et al. (10) (see appendix 1). The list consists of 11 criteria for internal validity, namely: 3 criteria regarding selection bias (a,b,c), 4 criteria for performance bias (d,e,g,h), 2 criteria regarding attrition bias (i,k) and two criteria for detection bias (f,j). All criteria were scored as 'yes', 'no' or 'unclear'. All unclear scores were later rated as 'no'. To be rated as of sufficient quality, 6 out of 11 criteria had to be met. Consensus was used to resolve disagreements and if disagreement or indistinctness persisted a third reviewer (JvW) was consulted.

Data extraction

Two reviewers (NvdM, JvW) independently documented the following characteristics of each included study:

1. Study design;
2. Participants: inclusion criteria; number of patients; sex; age; type of cancer and severity of the disease; inpatients/outpatients;
3. Intervention method: type of intervention in the experimental condition(s); type of intervention in the control conditions(s);
4. Outcome measures/instruments (recall of information): instruments used; timing of measurements; number of participants who completed the study in the experimental and control conditions; mean scores for experimental and control conditions; standard deviations in experimental and control conditions;
5. A short description of the results.

Data synthesis

Owing to diversity in the features of the interventions and the methods used to measure outcomes on recall of information, it was not possible to pool the data. Therefore a 'Best Evidence Synthesis' was conducted (see Table B.1) based on Van Tulder et al. (11) and adapted by Steultjens et al. (12).

The Best Evidence Synthesis was conducted by attributing various levels of evidence to the effectiveness of the interventions. The synthesis takes into account the design, the methodological quality and the outcomes of the studies.

Sensitivity analysis

A sensitivity analysis was performed to identify how sensitive the results of the Best Evidence Synthesis are to changes in the way it was conducted. The Best Evidence Synthesis was repeated in two different ways, using the following principles:

- Low quality studies were excluded.
- Studies were rated 'high-quality' if at least 4 (instead of 6) criteria of internal validity were met.

The results of the altered syntheses were then compared with those of the Best Evidence Synthesis and the sensitivity of the method was described.

Table B.1 Principles of Best Evidence Synthesis

Evidence:

Consistent, statistically significant findings in \geq two high quality (HQ) RCTs.

Moderate evidence:

Consistent, statistically significant findings in \geq one HQ RCT and in \geq one low quality (LQ) RCT or HQ CCT.

Limited evidence:

Statistically significant findings in \geq one HQ RCT

Or

Consistent, statistically significant findings in \geq two HQ CCTs (in absence of HQ RCTs).

Indicative findings:

Statistically significant findings in \geq one HQ CCT or LQ RCT (in absence of HQ RCTs)

No/Insufficient evidence:

If the number of studies with significant findings is $<$ 50% of the total number of studies within the same category of methodological quality and study design

Or

In case results of eligible studies do not meet one of the criteria for levels of evidence

Or

In case of conflicting results among RCTs and CCTs

Or

In case of no eligible studies

Results

Included studies

Application of the search strategy to the specified databases resulted in a total of 5173 hits (Table B.2). Based on titles and abstracts, the first author selected 43 studies which possibly met the seven inclusion criteria. These studies were tracked down and independently assessed on the seven inclusion criteria by the first two authors. Ten studies fulfilled all criteria. Eight of these articles were found in more than one database.

Table B.2 Selection of studies per database

Source	Hits per strategy	Number of relevant studies
PubMed 1990-2007	1722	9
PsychINFO 1990 - 2007	197	0
CINAHL 1990 - 2007	3005	(2)
Cochrane 1990-2007	249	(8)
Snow ball method		1
Total	5173	10

Study description

Table B.3 shows the results of the assessment of their methodological quality.

Table B.3 Methodological quality of included studies

First Author	Validity criteria met	Quality (>6)
<i>Randomized clinical trials (RCTs)</i>		
Bakker (13)	b,c,e,h,i,j	High
Brown (22)	a,b,c,g,j,k	High
Bruera (14)	a,b,d,e,f,h,i,j	High
Damian (21)	c,i,j	Low
Dunn (15)	a,c,e,h,j,k	High
McHugh (17)	a,b,e,h,k	Low
North (18)	c,h,i,j	Low
Ong (19)	c,d,e,h,i,j,k	High
<i>Controlled clinical designs (CCTs)</i>		
Hogbin (16)	a,e,h,j	Low
<i>Other Designs (RT)</i>		
Tattersall (20)	c,e,h,l,j	Low

The main characteristics and results of the included studies are presented in Table B.4.

Table B.4 Characteristics of included studies

First Author (reference)	Methods	Quality	Moment of measuring recall	Groups	Participants. Sex (%); mean age (range/ sd)	Conclusions
Bakker (13)	RCT	High	Between three and four weeks after the first visit	Group 1 (n=30): one to one nurse/patient teaching session Group 2 (n=31): one to one nurse/patient session and in addition a chemotherapy video to view at home	Outpatients (n=61) beginning a regimen of chemotherapy. Group 1: 84% is female; 65% 18-30 yrs, 36% 31-50 yrs, 55% 51-70 and 3% older than 70, group 2: 34% is female; 30% 31-50 yrs, 57% 51-70 yrs and 13% 70 yrs or older	The groups' mean number of responses was at least 80%. When comparing the groups' mean scores, no statistically significant difference was found, so an audiotape had no significant influence on recall when compared with verbal information alone
Brown (22)	RCT	High	Within ten days of the consultation	Group 1 (n=79): question prompt sheet (QPS) Group 2 (n=81): QPS and a doctor who actively addressed the QPS Group 3 (n=158): no QPS	Patients with heterogeneous cancers (n=318) attending an initial consultation. 44.3% is female; 56.1 (range 18-83). There were no significant differences between the three groups	Patients who received a QPS and whose doctor was proactive addressing the QPS recalled significantly more information in total and regarding treatment issues and side effects than those with a QPS alone or without a QPS

Table B.4 Continued

First Author (reference)	Methods	Quality	Moment of measuring recall	Groups	Participants. Sex (%); mean age (range/ sd)	Conclusions
Bruera (14)	RCT	High	One week after the initial consultation	Group 1 (n=31): written recommendations, no audiotape of the consultation Group 2 (n=29): written recommendations and an audiotape of the consultation	Outpatients with advanced cancer (N=60); 62.0 (sd=10)	The group who received written recommendations and an audiotape of the consultation recalled significantly more information in total and regarding medication than the group that received only written recommendations
Damian (21)	RCT	Low	Within three to nineteen days of the consultation	Group 1 (n=24): received a letter outlining their consultation. Group 2 (n=24): standard consultation without receiving a letter of the consultation	Patients with heterogeneous cancer (n=48) attending a general oncology outpatient clinic for a follow-up consultation. Group 1: 80% is female; 53.0 (range 21-70), group 2: 74% is female; 49.0 (range 28-71)	There was no significant difference in percentage of items recalled by the two groups

Table B.4 Continued

First Author (reference)	Methods	Quality	Moment of measuring recall	Groups	Participants. Sex (%); mean age (range/ sd)	Conclusions
Dunn (15)	RCT	High	One to three weeks after the consultation	Group 1 (n=31): consultation and an audiotape describing cancer in general terms Group 2 (n=30): consultation and an audiotape of the consultation Group 3 (n=31): no tape	Outpatients with cancer (n=142) attending their first consultation. 84% is female; 52.0	The consultation tape did not improve recall over the no tape control group, but the general tape caused a decrease of almost two items in total recall; spontaneous recall was significantly poorer with the general information tape
Hogbin (16)	CCT	Low	Following the consultation and two to three days preoperatively (within two weeks)	Group 1 (n=33): consultation and an audiotape of the consultation Group 2 (n=34): consultation, but no tape	Outpatients from various backgrounds with early breast cancer (n=67). All patients are female; Group 1: 57.5 (range 39-82), group 2: 57.9 (range 36-79)	After two weeks the group receiving the audiotape had a significantly higher score in recall than the group that did not receive a tape; greatest improvement was found on questions concerning the nature of tests already performed and those to be performed in the future

Table B.4 Continued

First Author (reference)	Methods	Quality	Moment of measuring recall	Groups	Participants. Sex (%); mean age (range/ sd)	Conclusions
McHugh (17)	RCT	Low	Six months after the initial consultation	Group 1 (n=63): consultation and an audiotape of the consultation Group 2 (n=54): consultation, but no tape	Outpatients (n=117) attending their first clinical consultation. Group 1: 63.5% is female; 45.0 (sd=15.8), group 2: 53.7% is female; 44.3 (sd=17.7)	Tape group patients correctly recalled more of the facts they had been given concerning their diagnosis and treatment than did control group patients; this effect was statistically significant for five of the nine categories of information examined
North (18)	RCT	Low	One week after the consultation	Group 1 (n=18): Consultation and audiotape of the consultation Group 2 (n=16): Consultation, but no tape	Outpatients (n=34) with advanced heterogeneous cancers. Group 1: 50% is female; 54.1, group 2: 56% is female; 56.4	The tape group were able to recall significantly more information concerning their illness, its treatment, treatment options and implications, how the illness had arisen and their prognosis than the no tape group

Table B.4 Continued

First Author (reference)	Methods	Quality	Moment of measuring recall	Groups	Participants. Sex (%); mean age (range/ sd)	Conclusions
Ong (19)	RCT	High	After one week and after three months	Group 1 (n=105): Consultation and audiotape of the consultation Group 2 (n=96): Consultation but no tape	Outpatients (N=201) referred to either the gynecology or medical outpatient clinic for their initial consultation. Group 1: 80% is female; 54.0 (range 25-85, sd=15.0), group 2: 83% is female; 53.0 (range 15-93, sd=16.5) information at both follow-up assessments	Patients provided with the tape were able to recall more information regarding all topics discussed during the consultation, except for trial procedure and chemotherapy; the tape group also recalled more information at both follow-up assessments
Tattersall (20)	Randomised cross-over trial	Low	Ten days after the consultation and seven to ten days after the first measurement	Group 1 (n=94): an audiotape after the consultation followed 7 to 10 days later by the letter Group 2 (n=88): a letter after the consultation followed 7 to 10 days later by the audiotape	Inpatients and outpatients (n=182) with heterogeneous cancers attending their first consultation. Group 1: 81% is female; 51.0 (range 28-78), group 2: 76% is female; 51.0 (range 16-80)	The audiotape of the consultation and the individualized letter did not differentially affect recall, which was on average 50% of the salient points identified by the physician

Intervention: audiotape or videotape

The first included study looked at an intervention for a pre-chemotherapy consultation (13). One group of patients received individual education from an oncology nurse, the others received an additional general take home instructional video. Patients completed a 23 item self-report questionnaire between three and four weeks after their first consultation to assess recall of information. The items were derived from literature and reflected the information presented by the nurses in the instructional sessions. Items were written as statements and required a yes/no response. The statements covered principles of chemotherapy, potential side effects and symptom management. Each score was reported as a percentage of correctly recalled information. Results showed that a general videotape, additional to verbal information, had no significant effect on recall when compared with verbal information only.

The second study assessed the relative impact of audiotaping physician consultations, additional to written recommendations, on patients' recall (14). Patients were divided in two groups: one group received an audiotaped recording of their consultation as well as written recommendations; the other group received written recommendations only. The audiotape contained information, advices and instructions on the definition, goal, possible side effects of chemotherapy and symptom management. Recall was assessed one week after the first consultation (during the second visit to the clinic). Ten questions were given to the patient. These questions addressed medication, disease information and care management and had dichotomous response categories ('yes'/'no' or 'true'/'false'). Patients appeared to recall more information when written information was combined with an audiotape of the consultation.

The third study compared the effect of two interventions on recall of information given prior to chemotherapy (15), namely patients receiving an general audiotape about cancer and patients receiving an audiotape of their specific consultation. A third group had the standard consultation. One to three weeks after the consultation with the oncologist, recall was assessed in a telephone interview with one open ended question: 'what did the doctor say during the consultation' (unprompted recall) and thirteen standardised questions regarding items that were regularly mentioned in the consultations:

'did the doctor mention anything about...' (prompted recall), e.g. regarding advantages and disadvantages of treatment, goals of treatment and practical details. Patients' answers were compared with the specific information given by the oncologist. Percentage of facts recalled accurately in total and within each category of information was reported. The results showed that a consultation tape did not improve recall in comparison with the no tape group and a general tape even decreased recall of information as compared to the control group.

The fourth study examined whether audiotapes of bad news consultations with a physician improved cancer patients' retention of information given as compared to patients that had a standard consultation (16). There were two assessments of recall, immediately after the consultation and again approximately two weeks later (two to three days before patients had breast surgery). Recall was measured with 'The Understanding Questionnaire' that was specifically constructed for this study and measured how well patients had understood different aspects of the treatment information, e.g. diagnosis, type of operation. The questionnaire contained a total of eighteen questions divided into seven sections. A score was determined for each patient after listening to the patients' taped consultation. Hogbin et al. (16) concluded that an audiotape of the consultation improved recall of information when compared with no tape.

The fifth study also investigated the effect of audiotaping a bad news consultation on recall (17). There were two groups of patients. One group had their consultation with a physician taped, but were not provided with a copy. The other received a copy of their consultation to take home. Recall was measured six months after the consultation using the 'The Information Retention Questionnaire'. This questionnaire required patients to recall particular aspects of the consultation regarding their diagnosis and treatment. Their answers were compared with the original recorded conversation. More information about the assessment of recall is not given in the article. McHugh et al. (17) concluded that an audiotape of a consultation improved recall compared with no tape.

The sixth study examined the effect of an audiotape on recall of information compared with a standard consultation (18). One group was given an audiotape of their consultation with an oncologist. The consultations of the other group were not audiotaped. Both before the consultation and one week after the consultation, a clinical nurse specialist asked eleven questions concerning patients' level of information about their illness. The questions covered the diagnosis, parts of the body involved, severity of the illness, choice of treatments, what treatment involved in terms of its aims, length, side effects and success rate. The conclusion was that an audiotape improved recall of information compared with no tape.

In the seventh included study (19), one group received an audiotape of the consultation with a gynaecologist or oncologist. Another group served as a control group and did not get an audiotape. To assess recall, each audio taped consultation was analyzed to itemize the actual information conveyed by the oncologist, against which patient recall of information was measured during a telephone interview. The information that was provided by the doctor could fall into nine categories, including diagnosis, prognosis, operation, trial, chemotherapy, radiotherapy, alternative treatment plan, direct side effects and other (long-term) consequences of treatment. Most of these categories consisted of subcategories. For each category, a percentage of right answers was calculated. The results showed that patients who received an audiotape recalled more information than patients who were not provided with an audiotape.

Intervention: audiotape versus letter

One study looked at the effects of an audiotape versus an individualized summary letter on recall after patients' first consultation with an oncologist (20). One group received the letter and then, after the first measurements, the tape. A second group received the tape followed by a letter, again after the first measurements. Both groups were phoned after ten days to answer recall questions regarding the information material they received first. Next, patients received the second form of information material and the telephone interview was repeated. The exact content of the telephone interview is not discussed in this article. Patients' answers were compared with salient points from the consultation that were selected by the doctor and focused on

treatment, prognosis, symptoms, advices and clinical research. Tattersall et al. (20) concluded that the audiotape of the consultation and the individualized letter did not differentially affect patient recall.

Intervention: summary letter

One included study investigated whether a summary letter to patients that outlined the oncology follow-up consultation and was written by the oncologist influenced their recall of information (21). One group of patients was given a letter after the consultation and a second group did not receive a letter. Recall was measured with a structured telephone interview and any misunderstanding was recorded. The interviews took place between three and nineteen days after the consultation. More information about the assessment of recall was not available in the article. Damian et al. (21) concluded that a summary letter outlining the consultation did not improve recall.

Intervention: Question Prompt Sheet (QPS)

One included study investigated the effects of a question prompt sheet (QPS) (22). A QPS is a structured list of questions designed to encourage patients to acquire information during a medical consultation. The QPS was provided 15-20 minutes prior to the initial consultation. There were three groups: patients who received standard care, patients who received a QPS which was actively endorsed by the doctor, and patients who received a QPS which was not actively endorsed. The QPS consisted of 17 questions commonly asked by patients. There was also space for patients to add additional questions. Recall was measured within ten days of the consultation using a structured telephone interview. 17 questions divided in 13 categories (15) were asked regarding specific areas which may have been covered during the consultation. Each item recalled was recorded and compared with the specific items mentioned by the oncologist during the consultation. The results showed that a QPS improved recall, but only when the doctor was proactive in addressing the sheet.

Data synthesis

Using the principles of the Best Evidence Synthesis (Table 1), taking into account the design, methodological quality and outcomes of the studies, the following conclusions can be drawn.

Audiotape of the consultation

There is scientific evidence that an audiotape of the consultation, complementary to oral information, has surplus value. Seven studies examined the effect of a specific audiotape on recall. In five of these studies a positive effect was found. Four studies, one high quality RCT (19) and three low quality CT studies (16-18) report added value of a specific audiotape upon a standard consultation only. In addition, one high quality RCT study (14) found that providing patients with a specific audiotape combined with a summary letter had a positive effect on recall when compared with a letter only. However, one high quality RCT study (15) did not find a positive effect of a specific audiotape on recall when compared with a standard consultation. A second study (low quality RT study) (20) found no difference between providing an audiotape or a letter, but it is not clear whether any one of the single interventions had added value compared with a standard consultation. The effects of videotapes have not been studied in isolation.

General audiotape

There is scientific evidence that a general audiotape, complementary to oral information, has no positive effect on recall when compared with verbal information alone. This evidence comes from two high quality RCT studies (13,15). In fact, general audiotapes might even inhibit recall of information (15), but the evidence for this conclusion comes from only one study and is therefore limited.

Summary letter

There is no scientific evidence that providing patients with a letter after the consultation improves their recall of information. One low quality RCT study (21) found no effect of a summary letter on recall. Another low quality randomized trial study (20) concluded that an individualized letter and an audiotape of the consultation did not differently affect patient recall. However, the added value of a letter or an audiotape in comparison with the standard consultation was not studied.

Question prompt sheet (QPS)

There is limited scientific evidence that a QPS improves recall, but only when the doctor is proactive in addressing patients questions. This evidence comes from one high quality RCT study (22).

Sensitivity analysis

The results of the data synthesis appeared not to be sensitive to the principles used in the Best Evidence Synthesis. The results remained comparable with those described above when the analysis was repeated with low quality studies excluded and when studies were rated to be of 'high' quality if 4 or more criteria were met.

Conclusion and discussion

This review on the effectiveness of interventions to improve cancer patients' recall of provided medical information presents the following conclusions. There is evidence that the provision of a specific audiotape, complementary to oral information, has added value for recall of information. There is also evidence that providing patients with a general audiotape has no added value compared with a standard consultation only; there is even limited evidence that a general audiotape might inhibit patients' recall of information. Furthermore, there is limited evidence that the use of a QPS has a positive effect on recall of information, provided that the physician actively endorses this sheet. There is no evidence for an effect of providing patients with a summary letter on recall, but hardly any studies investigated this topic.

These results suggest that interventions that were tailored to individual cancer patients (consultation audiotape or QPS) were most effective. Regarding a QPS, a possible explanation for this effect could be that a QPS helps patients to express their information needs. If the information is of personal relevance and relates to what the patient finds important, the information may be better recalled (23,24). This is in line with Kessels (2) who stated that specific information is better recalled than generally formulated information. This might also be the explanation for the effectiveness of providing an audiotape of the consultation, which is by definition specific and individualized.

McPherson et al. (25) noticed that specific information reduces the amount of information and ensures that only relevant information is provided, resulting in increased recall. Continuing assessment of cancer patients information needs is necessary, so that variations in preferences may be accommodated (25).

The majority of cancer patients find recordings of their consultations valuable (26) and tend to prefer receiving an audiotape of their own consultation over a standardized audiotape (27). Generally, patients also believe that a QPS is a useful tool (28), particularly to ask questions (29) or to achieve information needs and participation preferences (30). Krishna and Damato (31) found that patients highly appreciated receiving a copy of the letter from the ocular oncologist to the referring physician, and considered a useful method of information giving. Despite the enthusiasm of patients, there might be barriers to implement the provision of personalized information aids as the majority of doctors remain opposed to offering patients a tape or summary letter (32), citing issues as patient confidentiality and medico-legal concerns as reasons for their reluctance (33).

There have been several studies that measured the effects of audiotape provision on outcome measures other than recall. Receiving an audiotape of the consultation enhances patients' participation in subsequent consultations and in decisions about their care, but the effects on satisfaction are mixed (26). Patients' perception of having been provided with critical disease- and treatment-related information was found to be higher for patients that received an audiotape than for those who did not (34,35). Effects on anxiety, depression or quality of life have not been established yet (26). The use of a QPS also has positive effects on other outcome measures besides recall. A QPS in combination with a doctor who actively endorses this sheet shortened the consultation (22) and increased patient participation (22,36,37). However, two studies only found increased participation in the diagnostic (38) or prognostic phase of the disease (39) and no or mixed effects were found on patient satisfaction (22,36-38) and anxiety (22,28,36,37,40). The benefits of a QPS for cancer patients needs to be explored further in future research.

Hardly any studies investigated the effect of a summary letter or other written materials on recall in cancer patients. Therefore, this review could not

establish robust evidence for these interventions. Tattersall et al. (20) found no difference in actual recall of information between audiotapes or summary letters, but in the perception of cancer patients, audiotapes were significantly more effective than letters to remind them of what the oncologist had said. More research needs to be done on this topic. Studies into effects of written information on recall among other populations than cancer patients showed contradicting outcomes. Some studies concluded that recall of medical information could be increased by providing the participant with written information (41-43) and further improved by adding adjunct questions in a booklet or integrating printed patient education materials into face-to-face teaching (44). Other studies did not find a surplus value of written information, additional to verbal communication, on patients' recall of information (45,46,47-49). An explanation for these mixed results might be the enormous variation of written information in readability, i.e. comprehensibility, visual appeal, legibility, text style, typeface, size and layout (50).

The methodology of our systematic review has some limitations. The ten included studies in this review measured recall at different moments, some directly after the consultation or within a week, some within two to three weeks and one study measured recall even after six months (17). These differences make it difficult to compare results. When recall is measured a long time after the initial consultation, it seems impossible to distinguish between effects on recall caused by the intervention and other influences. Furthermore, most of the included studies had a small sample, from 16 to 105 (generally around 30) participants further complicating a comparison between studies. Most studies did not take into account that some factors (e.g. age, education level, anxiety, expectations, difficult medical terminology) may have a negative or positive effect on recall of information and did not control for these factors. Last but not least, the ten included studies differed in methods of measurement. Jansen et al. (51) indicated that different recall scores are obtained when using different measurement instruments. Because of the variety in study design, methods and differences in outcomes assessed, the data could not be synthesized by statistical techniques, such as meta-analysis. Additional research needs to be done to establish solid conclusions.

For now, it is important that professionals in cancer care realize that they can improve patients' recall of medical information, and thus achieve better outcomes, by using techniques that are tailored to the individual patient and by adapting information to the specific information needs of the patient.

References

1. Bishop O, Barlow JH, Hartley P, William N. Reflection on a multidisciplinary approach to evaluation of patient literature materials. *Health Educ* 1997; 56: 404-413.
2. Kessels, RPC. Patients' memory for medical information. *J R Soc Med* 2003; 96: 219-222.
3. Cameron, C. Patient compliance: Recognition of factors involved and suggestions for promoting compliance with therapeutic regimens. *J Adv Nurs* 1996; 24: 244-250.
4. Galloway S, Graydon J, Harrison D, Evans-Boyden B, Palmer-Wickham S, Burlein-Hall S, Rich-van der Bij L, West P, Blair A. Informational needs of women with a recent diagnosis of breast cancer: Development and initial testing of a tool. *J Adv Nurs* 1997; 25: 1175-1183.
5. Mossman J, Boudioni M, Slevin ML. Cancer information: A cost-effective intervention. *Eur J Cancer* 1999; 35: 1587-1591.
6. Anderson, JL. Patients recall of information and its relation to the nature of the consultation. In *Research in Psychology and Medicine*, Osborne D, Gruneberg MM and Eiser JR (Eds). Academic Press: London, 1979.
7. Ley, P. Memory for medical information. *Br J Soc Clin Psychol* 1979; 18: 245-256.
8. Ley, P. Satisfaction, compliance and communication. *Br J Clin Psychol* 1982; 21: 241-254.
9. Michie S, French D, Allanson A, Bobrow M, Marteau TM. 1997. Information recall in genetic counselling: A pilot study of its assessment. *Pat Educ Couns* 1997; 32: 93-100.
10. Van Tulder M, Furlan A, Bombardier C, Bouter L. Updated method guidelines for systematic reviews in the cochrane collaboration back review group. *Spine* 2003; 28 (12): 1290-1299.
11. Van Tulder MW, Cherkin DC, Berman B, Lao L, Koes BW. Acupuncture for low backpain. In *The Cochrane Library*. Update Software, issue 1: Oxford, 2002.
12. Steultjens EMJ, Dekker J, Bouter LM, Van de Nes JCM, Cardol M, Van den Ende CHM. Occupational therapy for multiple sclerosis (Protocol for a Cochrane Review). In *The Cochrane Library*. Update software, issue 3:Oxford, 2002.
13. Bakker DB, Blais D, Reed E, Vaillancourt C, Gervais S, Beaulieu P. Descriptive study to compare recall of information: Nurse-taught versus video supplement. *CONJ* 1999; 9: 115-120.
14. Bruera E, Pituskin E, Calder K, Neumann CM, Hanson J. The addition of an audiocassette recording of a consultation to written recommendations for patients with advanced cancer: A randomized, controlled trial. *Cancer* 1999; 86: 2420-2425.
15. Dunn SM, Butow PN, Tattersall MHN, Jones QJ, Sheldon JS, Taylor JJ, Sumich MD. General information tapes inhibit recall of the cancer consultation. *J Clin Oncol* 1993; 11: 2279-2285.
16. Hogbin B, Jenkins VA, Parkin AJ. Remembering 'bad news' consultations: An evaluation of tape-recorded consultations. *Psycho-Oncol* 1992; 1: 147-154.

17. McHugh P, Lewis S, Ford S, Newlands E, Rustin G, Coombes C, Smith D, O'Reilly S, Fallowfield L. The efficacy of audiotapes in promoting psychological well-being in cancer patients: A randomised, controlled trial. *Br J Cancer* 1995; 71(2): 388-392.
18. North N, Cornbleet MA, Knowles G, Leonard RC. Information giving in oncology: A preliminary study of tape-recorder use. *Br J Clin Psychol* 1992;31:357-359.
19. Ong LML, Visser MRM, Lammes FB, Van der Velden J, Kuenen BC, Haes JCJM. Effect of providing cancer patients with the audiotaped initial consultation on satisfaction, recall and quality of life: A randomized, double-blind study. *J Clin Oncol* 2000; 18(16): 3052-3060.
20. Tattersall MH, Butow PN, Griffin AM, Dunn SM. The take-home message: Patients prefer consultation audiotapes to summary letters. *J Clin Oncol* 1994; 12 (6): 1305-11.
21. Damian D, Tattersell MHN. Letters to patients: Improving communication in cancer care. *Lancet* 1991; 338: 923-926.
22. Brown RF, Butow PN, Dunn SM, Tattersall MH. Promoting patient participation and shortening cancer consultations: A randomised trial. *Br Journal Cancer* 2001; 85 (9): 1273-1279.
23. Craik F, Lockhart R. Levels of processing: A framework for memory research. *J. verbal learn. verbal behav.* 1972; 11: 671-684.
24. Ingram, RE. Information processing and feedback: Effects of mood and information favourability on the cognitive processing of personally relevant information. *Cognitive Therapy and Research* 1984; 8: 371-386.
25. McPherson CJ, Higginson IJ, Hearn J. Effective methods of giving information in cancer: A systematic literature review of randomized controlled trials. *J Public Health Med* 2001; 23 (3): 227-234.
26. Scott JT, Entwistle VA, Sowden AJ, Watt I. Giving tape recordings or written summaries of consultations to people with cancer: A systematic review. *Health Expect* 2001; 4: 162-169.
27. Hack TH, Whelan T, Olivotto IA, Weir L, Bultz BD, Magwood B, Ashbury F, Brady J. Standardized audiotape versus recorded consultation to enhance informed consent to a clinical trial in breast oncology. *Psycho-Oncol* 2007; 16(4): 371-6
28. Clayton J, Butow P, Tattersall M, Chye R, Noel M, Davis JM, Glare P. Asking questions can help: Development and preliminary evaluation of a question prompt list for palliative care patients. *Br J Cancer* 2003; 89: 2069-2077.
29. Glynne-Jones R, Ostler P, Lumley-Graybow S, Chait I, Hughes R, Grainger J, Leverton TJ. Can I look at my list? An evaluation of a 'prompt sheet' within an oncology outpatient clinic. *Clin Oncol (R Coll Radiol)* 2006; 18: 395-400.
30. McJannett M, Butow P, Tattersall MH, Thompson JF. Asking questions can help: Development of a question prompt sheet list for cancer patients seeing a surgeon. *Eur J Cancer Prev* 2003; 12: 397-405.

31. Krishna Y, Damato BE. Patient attitudes to receiving copies of outpatient clinic letters from the ocular oncologist to the referring ophthalmologist and GP. *Eye* 2005; 19: 1200-1204.
32. McConnell D, Butow PN, Tattersall MH. Audiotapes and letters to patients: The practice and views of oncologists, surgeons and general practitioners. *Br J Cancer* 1999; 79: 1782-1788.
33. Tattersall MH, Butow PN. Consultation audio tapes: An underused cancer patient information aid and clinical research tool. *Lancet Oncol* 2002; 3: 431-437.
34. Hack TF, Pickles T, Bultz BB, Ruether JD, Weir LM, Degner LF, Mackey JR. Impact of providing audiotapes of primary adjuvant treatment consultation to women with breast cancer: A multisite, randomized, controlled trial. *J Clin Oncol* 2003; 21: 4138-4144.
35. Hack TF, Pickles T, Bultz BD, Dean Ruether J, Degner LF. Impact of providing audiotapes of primary treatment consultations to men with prostate cancer: A multi-site, randomized, controlled trial. *Psycho-Oncol* 2006; 21.
36. Brown R, Butow P, Boyer MJ, Tattersall MHN. Promoting patient participation in the cancer consultation: Evaluation of a prompt sheet and coaching in question-asking. *Br J Cancer* 1999; 80: 242-248.
37. Butow P, Devine R, Boyer M, Pendlebury S, Jackson M, Tattersall MHN. Cancer consultation preparation package: Changing patients but not physicians is not enough. *J Clin Oncol* 2004;22:401-4409.
38. Bruera E, Sweeney C, Willey J, Palmer JL, Tolley S, Rosales M, Ripamonti C. Breast cancer patient perception of the helpfulness of a prompt sheet versus a general information sheet during outpatient consultation: A randomized, controlled trial. *J Pain Symptom Manage* 2003; 25: 412-419.
39. Butow PN, Dunn SM, Tattersall MH, Jones OH. Patient participation in the cancer consultation: Evaluation of a question prompt sheet. *Ann Oncol* 1994; 5: 199-204.
40. Ambler N, Rumsey N, Harcourt D, Khan F, Cawthorn S, Barker J. Specialist nurse counsellor interventions at the time of diagnosis of breast cancer: Comparing 'advocacy' with a conventional approach. *J Adv Nurs* 1999; 29: 445-453.
41. Higgins L, Ambrose P. The effect of adjunct questions on older adults' recall of information from a patient education booklet. *Pat Educ Couns* 1995; 25: 67-74.
42. Partin MR, Nelson D, Radosevich D, Nugent S, Flood AB, Dillon N, Holtzman J, Haas M, Wilt TJ. Randomized trial examining the effect of two prostate cancer screening educational interventions on patient knowledge, preferences and behaviors. *J Gen Intern Med* 2004; 19: 835-842.
43. Sandler DA, Mitchell JRA, Fellows A, Garner ST. Is an information booklet for patients leaving hospital helpful and useful? *Br Med J* 1989; 298: 870-874.
44. Webber D, Higgins L, Baker V. Enhancing recall of information from a patient education booklet: A trial using cardiomyopathy patients. *Pat Educ Couns* 2001; 44: 263-270.
45. Clarke Moloney M, Moore A, Adelola OA, Burke PE, McGee H, Grace PA. Information leaflets for venous leg ulcer patients: Are they effective? *J Wound Care* 2005; 14: 75-77.

46. Isaacman DJ, Purvis K, Gyuro J, Anderson Y, Smith D. 1992. Standardized instructions: Do they improve communication of discharge information from the emergency department. *Pediatrics* 1992; 89: 1204-1208
47. Ives NJ, Troop M, Waters A, Davies S, Higgs C, Easterbrook PJ. Does an HIV clinical trial information booklet improve patient knowledge and understanding of HIV clinical trials? *HIV Med* 2001; 2: 241-249.
48. Little P, Roberts L, Blowers H, Garwood J, Cantell T, Lamgridge J, Chapman J. Should we give detailed advice and information booklets to patients with back pain? A randomized controlled factorial trial of a self-management booklet and doctor advice to take exercise for back pain. *Spine* 2001; 26: 2065-2072.
49. Pesudovs K, Luscombe CK, Coster DJ. Recall from informed consent counseling for cataract surgery. *J Law Med* 2006; 13: 496-504.
50. Arthur, VAM. Written patient information: a review of the literature. *J Adv Nurs* 1995; 21: 1081-1086.
51. Jansen, J., van Weert, J., van der Meulen, N., van Dulmen, S., Heeren, T., & Bensing, J. (2008b). Recall in older cancer patients: measuring memory for medical information. *Gerontologist*, 48(2), 149-157

Appendix B.1 Criteria list for assessment of the methodological quality

Validity criteria:	yes	No	Don't know
A Was the method of randomisation adequate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B Was the treatment allocation concealed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C Were the groups similar at baseline regarding the most important prognostic indicators?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D Was the patient blinded to the intervention?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E Was the care provider blinded to the intervention?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F Was the outcome assessor blinded to the intervention?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G Were co-interventions avoided or similar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H Was the compliance acceptable in all groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I Was the drop out rate described and acceptable?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J Was the timing of the outcome assessment in all groups similar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K Did the analysis include an intention-to-treat analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Methodological quality:

- High quality; the study adequately fulfilled 50% or more of the validity criteria (6 or more out of 11 criteria)
- Low quality; the study fulfilled less than 50% of the validity criteria (< 6 out of 11 criteria)

Remarks:

.....

Operationalisation of the criteria list

- A Was the method of randomisation adequate, e.g. at patient level? Examples of adequate methods are computer generated random number table and use of sealed opaque envelopes.
Score yes if the above is the case. Score no if a transparent system is used and score don't know ¹ when the method of randomization is not described in the article.
- B Was the assignment generated by an independent person not responsible for determining the eligibility of the patients? This person has no information about the persons included in the study and has no influence on the assignment sequence or on the decision about the eligibility of the patients.
Score yes when the assignment has been taken place by an independent person. Score no if the above is not the case and score don't know if no information is given about who generated the assignment.
- C Are important prognostic indicators assessed at baseline? Are there no substantial differences between the intervention group and the control group (for example regarding age, sex, type of cancer, duration of the disease, stadium of the disease, cognitive status and type of treatment).
Score yes if the above is the case and score no if there are differences regarding the prognostic indicators at baseline that could undermine post-intervention differences. Score also no if no testing has been done to check if there were actual differences (a table with prognostic indicators without explanation is not enough). Score don't know when no information had been given about prognostic indicators.
- D Was the patient blinded to the intervention?
The reviewer determines if enough information is given in order to score a 'yes'. Score don't know if no information is given.
- E Was the care provider blinded to the intervention?
The reviewer determines if enough information is given in order to score a 'yes'. Score don't know if no information is given.
- F Was the outcome assessor blinded to the intervention?
The reviewer determines if enough information is given in order to score a 'yes'. Score don't know if no information is given.

¹ All don't know scores are eventually counted as no.

- G Were co-interventions avoided in the design or were they similar between the intervention groups and control group?
Score yes if the above is the case. Score no if there were co-interventions, not similar for the different groups. Score also no when no information has been given about co-interventions (so, not tested is also no).
Note. This criterium cannot be decisive in determining low quality of an article.
- H Was the compliance rate among patients evaluated (e.g. did they view the received video or read the written material)?
Score yes if the percentage of patients that used the intervention is above 70% in all groups. Score no if this percentage is below 70% and score don't know if no information about compliance has been given.
- I Is the number of patients described (and reasons given) that were included in the study but did not complete the intervention or were excluded from analysis? Is this percentage of withdrawals or drop-outs acceptable?
Score yes if there is information from 80-100% of the randomised patients about the outcome assessment of recall. Score no if there is information from less than 80% of the randomised patients and score don't know if no information about withdrawals or drop-outs has been given.
- J Was the timing of the outcome assessment in all groups similar?
Score yes if the above is the case (score also yes if a range is described, provided that this range does not have a large spread, for example more than three months). Score no if the timing of outcome assessment was not similar for all groups and score don't know if no information about the timing was given.
- K Was all available data included for analysis (intention to treat)? This means that all randomised patients were analysed in the group they were assigned to regardless of non-compliance and co-interventions.
Score yes if the above is the case, score no when the analysis did not include an intention to treat analysis. Score don't know if no information about intention to treat is given.

References

A

- Aapro, M., & Johnson, C. D. (2007). The elderly: geriatric oncology finally deserving adequate attention. *European Journal of Cancer*, 43(16), 2312-2314.
- Aapro, M. S. (2005). The frail are not always elderly. *Journal of Clinical Oncology*, 23(10), 2121-2122.
- Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., & de Haes, J. C. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute*, 85(5), 365-376.
- Abraham, C., & Michie, S. (2008). A taxonomy of behavior change techniques used in interventions. *Health Psychology*, 27(3), 379-387.
- Adelman, R. D., Greene, M. G., & Charon, R. (1987). The physician-elderly patient-companion triad in the medical encounter: the development of a conceptual framework and research agenda. *Gerontologist*, 27(6), 729-734.
- Adelman, R. D., Greene, M. G., Charon, R., & Friedmann, E. (1992). The Content of Physician and Elderly Patient Interaction in the Medical Primary Care Encounter. *Communication Research*, 19(3), 370-380.
- Adelman, R. D., Greene, M. G., & Ory, M. G. (2000). Communication between older patients and their physicians. *Clinics in Geriatric Medicine*, 16(1), 16(1), XIII-XIV.
- Anderson, W. G., Alexander, S. C., Rodriguez, K. L., Jeffreys, A. S., Olsen, M. K., Pollak, K. I., Tulskey, J. A., & Arnold, R. M. (2008). "What concerns me is..." Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer*, 16(7), 803-811.
- Arora, N. K. (2008). Advancing research on patient-centered cancer communication. *Patient Education and Counseling*, 70(3), 301-302.

B

- Back, A. L., & Arnold, R. M. (2006a). Discussing prognosis: "how much do you want to know?" talking to patients who are prepared for explicit information. *Journal of Clinical Oncology*, 24(25), 4209-4213.
- Back, A. L., & Arnold, R. M. (2006b). Discussing prognosis: "how much do you want to know?" talking to patients who do not want information or who are ambivalent. *Journal of Clinical Oncology*, 24(25), 4214-4217.
- Bakker, D. A., Blais, D., Reed, E., Vaillancourt, C., Gervais, S., & Beaulieu, P. (1999). Descriptive study to compare patient recall of information: nurse-taught versus video supplement. *Canadian Oncology Nursing Journal*, 9(3), 115-120.

- Balducci, L. (2003). New paradigms for treating elderly patients with cancer: the comprehensive geriatric assessment and guidelines for supportive care. *Journal of Supportive Oncology*, 1(4 Suppl 2), 30-37.
- Balducci, L. (2007). Aging, frailty, and chemotherapy. *Cancer Control*, 14(1), 7-12.
- Baltes, M. M., & Carstensen, L. L. (1996). The process of successful ageing. *Ageing and Society*, 16, 397-422.
- Baltes, P. B. (1997). On the incomplete architecture of human ontogeny. Selection, optimization, and compensation as foundation of developmental theory. *American Psychologist*, 52(4), 366-380.
- Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation (Vol. 1). New York: Cambridge University Press.
- Baltes, P. B., & Lindenberger, U. (1997). Emergence of a powerful connection between sensory and cognitive functions across the adult life span: a new window to the study of cognitive aging? *Psychology and Aging*, 12(1), 12-21.
- Barry, C. A., Stevenson, F. A., Britten, N., Barber, N., & Bradley, C. P. (2001). Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Social Science & Medicine*, 53(4), 487-505.
- Behandelwijzer chemotherapie. Algemene informatie over de behandeling met chemotherapie voor de patient [Treatment Guide to Chemotherapy. General information for patients about chemotherapy treatment]. www.ikcnet.nl (July, 2008)
- Beisecker, A. E. (1989). The influence of a companion on the doctor-elderly patient interaction. *Health Communication*, 1(1), 55-70.
- Beisecker, A. E. (1996). Older persons' medical encounters and their outcomes. *Research on Aging*, 18(1), 9-31.
- Beisecker, A. E., Brecheisen, M. A., Ashworth, J., & Hayes, J. (1996). Perceptions of the role of cancer patients' companions during medical appointments. *Journal of Psychosocial Oncology*, 14(4), 29-45.
- Beisecker, A. E. M., W.P. (1994). Oncologists' perceptions of the effects of cancer patients' companions on physician-patient interactions. *Journal of Psychosocial Oncology*, 12(1/2).
- Bensing, J. M. (2000). Bridging the gap. The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counseling*, 39, 17-25.
- Berg, C. A., Smith, T. W., Ko, K. J., Henry, N. J. M., Florsheim, P., Pearce, G., Uchino, B. N., Skinner, M. A., Beveridge, R. A., Story, N., & Glazer, K. (2007). Task control and cognitive abilities of self and spouse in collaboration in middle-aged and older couples. *Psychology and Aging*, 22(3), 420-427.
- Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, 133(6), 920-954.
- Berg, C. A., Wiebe, D. J., Butner, J., Bloor, L., Bradstreet, C., Upchurch, R., Hayes, J., Stephenson, R., Nail, L., & Patton, G. (2008). Collaborative coping and daily mood in couples dealing with prostate cancer. *Psychology and Aging*, 23(3), 505-516.

- Blank, T. O., & Bellizzi, K. M. (2008). A gerontologic perspective on cancer and aging. *Cancer*, 112(11 Suppl), 2569-2576.
- Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P., & Boyes, A. (2000). Evaluation of an instrument to assess the needs of patients with cancer. Supportive Care Review Group. *Cancer*, 88(1), 217-225.
- Bopp, K. L., & Verhaeghen, P. (2005). Aging and verbal memory span: a meta-analysis. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences*, 60(5), 223-233.
- Bourgeois, L. G., & Lotocki, R. (1999). Sexuality and gynaecological cancer: a needs assessment. *Canadian Journal of Human Sexuality*, 8(4), 231-240.
- Brown, A., & Draper, P. (2003). Accommodative speech and terms of endearment: elements of a language mode often experienced by older adults. *Journal of Advanced Nursing*, 41(1), 15-21.
- Brown, R. F., Butow, P. N., Dunn, S. M., & Tattersall, M. H. N. (2001). Promoting patient participation and shortening cancer consultations: a randomised trial. *British Journal of Cancer*, 85(9), 1273-1279.
- Brown, S. C., Glass, J. M., & Park, D. C. (2002). The relationship of pain and depression to cognitive function in rheumatoid arthritis patients. *Pain*, 96(3), 279-284.
- Brown, S. C., & Park, D. C. (2003). Theoretical models of cognitive aging and implications for translational research in medicine. *Gerontologist*, 43 Spec No 1, 57-67.
- Bruera, E., Pituskin, E., Calder, K., Neumann, C. M., & Hanson, J. (1999). The addition of an audiocassette recording of a consultation to written recommendations for patients with advanced cancer: A randomized, controlled trial. *Cancer*, 86(11), 2420-2425.
- Butow, P. N. (2005). Commentary on: The communication goals and needs of cancer patients: a review. *Psycho-Oncology*, 14(10), 846-847.
- Butow, P. N., Brindle, E., McConnell, D., Boakes, R., & Tattersall, M. H. N. (1998). Information booklets about cancer: factors influencing patient satisfaction and utilisation. *Patient Education and Counseling*, 33, 129-141.
- Butow, P. N., Brown, R. F., Cogar, S., Tattersall, M. H., & Dunn, S. M. (2002a). Oncologists' reactions to cancer patients' verbal cues. *Psycho-Oncology*, 11(1), 47-58.
- Butow, P. N., Dunn, S. M., Tattersall, M. H. N., & Jones, Q. J. (1995). Computer-based interaction analysis of the cancer consultation. *British Journal of Cancer*, 71(5), 1115-1121.

C

- Callahan, E. J., Stange, K. C., Zyzanski, S. J., Goodwin, M. A., Flocke, S. A., & Bertakis, K. D. (2004). Physician-elder interaction in community family practice. *Journal of the American Board of Family Practice*, 17(1), 19-25.
- Campbell, L., & Kashy, D. A. (2002). Estimating actor, partner, and interaction effects for dyadic data using PROC MIXED and HLM: A user-friendly guide. *Personal Relationships*, 9(3), 327-342.

- Carelle, N., Piotto, E., Bellanger, A., Germanaud, J., Thuillier, A., & Khayat, D. (2002). Changing patient perceptions of the side effects of cancer chemotherapy. *Cancer*, 95(1), 155-163.
- Caris-Verhallen, W., Timmermans, L., & van Dulmen, S. (2004). Observation of nurse-patient interaction in oncology: review of assessment instruments. *Patient Education and Counseling*, 54(3), 307-320.
- Caris-Verhallen, W. M. (1999). Nurse-patient communication in elderly care. Universiteit Utrecht, Utrecht, The Netherlands.
- Caris-Verhallen, W. M., Kerkstra, A., & Bensing, J. M. (1997). The role of communication in nursing care for elderly people: a review of the literature. *Journal of Advanced Nursing*, 25(5), 915-933.
- Carlson, L. E., Feldman-Stewart, D., Tishelman, C., & Brundage, M. D. (2005). Patient-professional communication research in cancer: an integrative review of research methods in the context of a conceptual framework. *Psycho-Oncology*, 14(10), 812-828.
- Carstensen, L. L., Isaacowitz, D. M., & Charles, S. T. (1999). Taking time seriously - A theory of socioemotional selectivity. *American Psychologist*, 54(3), 165-181.
- Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K., & March, V. (1980). Information and participation preferences among cancer patients. *Annals of Internal Medicine*, 92(6), 832-836.
- Cegala, D. J., McClure, L., Marinelli, T. M., & Post, D. M. (2000). The effects of communication skills training on patients' participation during medical interviews. *Patient Education and Counseling*, 41(2), 209-222.
- Chouliara, Z., Kearney, N., Stott, D., Molassiotis, A., & Miller, M. (2004a). Perceptions of older people with cancer of information, decision making and treatment: a systematic review of selected literature. *Annals of Oncology*, 15(11), 1596-1602.
- Chouliara, Z., Kearney, N., Worth, A., & Stott, D. (2004b). Challenges in conducting research with hospitalized older people with cancer: drawing from the experience of an ongoing interview-based project. *European Journal of Cancer Care (Engl.)*, 13(5), 409-415.
- Christianson, S. A. (1992). Emotional stress and eyewitness memory: a critical review. *Psychological Bulletin*, 112(2), 284-309.
- Clayman, M. L., Roter, D., Wissow, L. S., & Bandeen-Roche, K. (2005). Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. *Social Science & Medicine*, 60(7), 1583-1591.
- Clayton, J. M., Hancock, K., Parker, S., Butow, P. N., Walder, S., Carrick, S., Currow, D., Ghera, D., Glare, P., Hagerty, R., Olver, I. N., & Tattersall, M. H. (2008). Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-Oncology*, 17(7), 641-659.

- Clayton, J. M., Hancock, K. M., Butow, P. N., Tattersall, M. H., Currow, D. C., Adler, J., Aranda, S., Auret, K., Boyle, F., Britton, A., Chye, R., Clark, K., Davidson, P., Davis, J. M., Girgis, A., Graham, S., Hardy, J., Introna, K., Kearsley, J., Kerridge, I., Kristjanson, L., Martin, P., McBride, A., Meller, A., Mitchell, G., Moore, A., Noble, B., Olver, I., Parker, S., Peters, M., Saul, P., Stewart, C., Swinburne, L., Tobin, B., Tuckwell, K., & Yates, P. (2007b). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Medical Journal of Australia*, 186(12 Suppl), S77, S79, S83-108.
- Cohen, H. J. (2007). The cancer aging interface: a research agenda. *Journal of Clinical Oncology*, 25(14), 1945-1948.
- Collins, S. (2005). Explanations in consultations: the combined effectiveness of doctors' and nurses' communication with patients. *Medical Education*, 39(8), 785-796.
- Conill, C., Verger, E., & Salamero, M. (1990). Performance status assessment in cancer patients. *Cancer*, 65(8), 1864-1866.
- Corney, R., Everett, H., Howells, A., & Crowther, M. (1992). The care of patients undergoing surgery for gynaecological cancer: the need for information, emotional support and counselling. *Journal of Advanced Nursing*, 17(6), 667-671.
- Craik, F. I. M., & Lockhart, R. S. (1972). Levels of processing: a framework for memory research. *Journal of Verbal Learning and Verbal Behavior*, 11(6), 671-684.
- Craik, F. I. M., & McDowd, J. M. (1987). Age-Differences in Recall and Recognition. *Journal of Experimental Psychology-Learning Memory and Cognition*, 13(3), 474-479.

D

- Darowski, E. S., Helder, E., Zacks, R. T., Hasher, L., & Hambrick, D. Z. (2008). Age-related differences in cognition: the role of distraction control. *Neuropsychology*, 22(5), 638-644.
- de Haes, H. (2006). Dilemmas in patient centeredness and shared decision making: a case for vulnerability. *Patient Education and Counseling*, 62(3), 291-298.
- De Valck, C., Bensing, J. M., Bruynooghe, R., & Batenburg, V. (2001). Cure-oriented versus care-oriented attitudes in medicine. *Patient Education and Counseling*, 45(2), 119-126.
- De Valck, C., Bruynooghe, R., Bensing, J. M., Kerssens, J. J., & Hulsman, R. L. (2001). Cue-responding in a simulated bad news situation: Exploring a stress hypothesis. *Journal of Health Psychology*, 6(5), 585-596.
- Del Piccolo, L., Mazzi, M. A., Dunn, G., Sandri, M., & Zimmermann, C. (2007). Sequence analysis in multilevel models. A study on different sources of patient cues in medical consultations. *Social Science & Medicine*, 65(11), 2357-2370.
- Delafuente, J. C. (2003). Understanding and preventing drug interactions in elderly patients. *Critical Reviews in Oncology / Hematology*, 48(2), 133-143.
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychology*, 23(2), 207-218.

- Dimoska, A., Tattersall, M. H. N., Butow, P. N., Shepherd, H., & Kinnersley, P. (2008). Can a "Prompt List" empower cancer patients to ask relevant questions? *Cancer*, 113(2), 225-237.
- Dunn, G. (1989). *Design and analysis of reliability studies: the statistical evaluation of measurement errors*. New York: Oxford University Press.
- Dunn, J., Steginga, S. K., Rose, P., Scott, J., & Allison, R. (2004). Evaluating patient education materials about radiation therapy. *Patient Education and Counseling*, 52(3), 325-332.
- Dunn, S. M., Butow, P. N., Tattersall, M. H. N., Jones, Q. J., Sheldon, J. S., Taylor, J. J., & Sumich, M. D. (1993). General information tapes inhibit recall of the cancer consultation. *Journal of Clinical Oncology*, 11(11), 2279-2285.
- Dutch Cancer Society. (2004). *Kanker in Nederland. Trends, prognoses en implicaties voor zorgvraag* (Cancer in the Netherlands. Trends, prognoses, and implications for health care requirements).

E

- Easterbrook, J. A. (1959). The effect of emotion on cue utilization and the organization of behavior. *Psychological Review*, 66(3), 183-201.
- Ebner, N. C., Freund, A. M., & Baltes, P. B. (2006). Developmental changes in personal goal orientation from young to late adulthood: from striving for gains to maintenance and prevention of losses. *Psychology and Aging*, 21(4), 664-678.
- Eggly, S., Penner, L., Albrecht, T. L., Cline, R. J., Foster, T., Naughton, M., Peterson, A., & Ruckdeschel, J. C. (2006a). Discussing bad news in the outpatient oncology clinic: rethinking current communication guidelines. *Journal of Clinical Oncology*, 24(4), 716-719.
- Eggly, S., Penner, L. A., Greene, M., Harper, F. W., Ruckdeschel, J. C., & Albrecht, T. L. (2006b). Information seeking during "bad news" oncology interactions: Question asking by patients and their companions. *Social Science & Medicine*, 63(11), 2974-2985.
- Eide, H., Quera, V., Graugaard, P., & Finset, A. (2004). Physician-patient dialogue surrounding patients' expression of concern: applying sequence analysis to RIAS. *Social Science & Medicine*, 59(1), 145-155.
- Ellingson, L. L. (2002). The roles of companions in geriatric patient-interdisciplinary oncology team interactions. *Journal of Aging Studies*, 16(4), 361-382.
- Engel, G. L. (1988). *How much longer must medicine's science be bound by a 17th century world view. The Task of Medicine: Dialogue at Wickenburg*. Menlo Park, California: Henry Kaiser Family Foundation, 113-136.
- Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., & Duberstein, P. R. (2005). Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Social Science & Medicine*, 61(7), 1516-1528.

- Epstein, R. M., & Street, R. L. J. (2007). Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225.
- Extermann, M., & Hurria, A. (2007). Comprehensive geriatric assessment for older patients with cancer. *Journal of Clinical Oncology*, 25(14), 1824-1831.

F

- Fallowfield, L., & Jenkins, V. (1999). Effective communication skills are the key to good cancer care. *European Journal of Cancer*, 35(11), 1592-1597.
- Fitch, M., Gray, R. E., & Franssen, E. (2000). Perspectives on living with ovarian cancer: young women's views. *Canadian Oncology Nursing Journal*, 10(3), 101-108.
- Fitzsimmons, D., Hawker, S. E., Simmonds, P., George, S. L., Johnson, C. D., & Corner, J. L. (2005). Nurse-led models of chemotherapy care: mixed economy or nurse-doctor substitution? *Journal of Advanced Nursing*, 50(3), 244-252.
- Fitzsimmons, D., Hawker, S. E., Simmonds, P., George, S. L., Johnson, C. D., & Corner, J. L. (2005). Nurse-led models of chemotherapy care: mixed economy or nurse-doctor substitution? *Journal of Advanced Nursing*, 50(3), 244-252.
- Flocke, S. A., & Stange, K. C. (2004). Direct observation and patient recall of health behavior advice. *Preventive Medicine*, 38(3), 343-349.
- Fogarty, L. A., Curbow, B. A., Wingard, J. R., McDonnell, K., & Somerfield, M. R. (1999). Can 40 seconds of compassion reduce patient anxiety? *Journal of Clinical Oncology*, 17(1), 371-379.
- Ford, S., Fallowfield, L., & Lewis, S. (1994). Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations. *British Journal of Cancer*, 70, 767-770.
- Ford, S., Hall, A., Ratcliffe, D., & Fallowfield, L. (2000). The medical interaction process system (MIPS): An instrument for analysing interviews of oncologists and patients with cancer. *Social Science & Medicine*, 50, 553-566.
- Forgas, J. P. (1995). Mood and judgment: the affect infusion model (AIM). *Psychological Bulletin*, 117(1), 39-66.
- Fox, J. (1997). Applied regression analysis, linear models, and related methods. London: Sage.
- Franssen, S. J., Lagarde, S. M., van Werven, J. R., Smets, E. M., Tran, T. C., Plukker, J. T., van Lanschot, J. J., & De Haes, J. C. (in Press). Psychological factors and preferences for communicating prognosis in esophageal cancer patients. *Psycho-Oncology*.
- Friis, L. S., Elverdam, B., & Schmidt, K. G. (2003). The patient's perspective: a qualitative study of acute myeloid leukaemia patients' need for information and their information-seeking behaviour. *Support Care Cancer*, 11(3), 162-170.

G

- Gabrijel, S., Grize, L., Helfenstein, E., Brutsche, M., Grossman, P., Tamm, M., & Kiss, A. (2008). Receiving the diagnosis of lung cancer: patient recall of information and satisfaction with physician communication. *Journal of Clinical Oncology*, 26(2), 297-302.
- Galloway, S. C., & Graydon, J. E. (1996). Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer Nursing*, 19(2), 112-117.
- Ganz, P. A., Lee, J. J., Sim, M. S., Polinsky, M. L., & Schag, C. A. (1992). Exploring the influence of multiple variables on the relationship of age to quality of life in women with breast cancer. *Journal of Clinical Epidemiology*, 45(5), 473-485.
- Gattellari, M., Butow, P. N., & Tattersall, M. H. (2001). Sharing decisions in cancer care. *Social Science & Medicine*, 52(12), 1865-1878.
- Gattellari, M., Butow, P. N., Tattersall, M. H., Dunn, S. M., & MacLeod, C. A. (1999). Misunderstanding in cancer patients: why shoot the messenger? *Annals of Oncology*, 10(1), 39-46.
- Giacalone, A., Blandino, M., Talamini, R., Bortolus, R., Spazzapan, S., Valentini, M., & Tirelli, U. (2007). What elderly cancer patients want to know? Differences among elderly and young patients. *Psycho-Oncology*, 16(4), 365-370.
- Giacalone, A., Talamini, R., Spina, M., Fratino, L., Spazzapan, S., & Tirelli, U. (2008). Can the caregiver replace his/her elderly cancer patient in the physician-patient line of communication? *Support Care Cancer*, 16(10), 1157-1162.
- Gijzen, R., Hoeymans, N., Schellevis, F. G., Ruwaard, D., Satariano, W. A., & van den Bos, G. A. (2001). Causes and consequences of comorbidity: a review. *Journal of Clinical Epidemiology*, 54(7), 661-674.
- Glasser, M., Prohaska, T., & Gravdal, J. (2001). Elderly patients and their accompanying caregivers on medical visits. *Research on Aging*, 23(3), 326-348.
- Gould, O. N., Osborn, C., Krein, H., & Mortenson, M. (2002). Collaborative recall in married and unacquainted dyads. *International Journal of Behavioral Development*, 26(1), 36-44.
- Grady, C. L., & Craik, F. I. (2000). Changes in memory processing with age. *Current Opinion in Neurobiology*, 10(2), 224-231.
- Graydon, J., Galloway, S., Palmer-Wickham, S., Harrison, D., Rich-van der Bij, L., West, P., Burlein-Hall, S., & Evans-Boyden, B. (1997). Information needs of women during early treatment for breast cancer. *Journal of Advanced Nursing*, 26(1), 59-64.
- Greene, M. G., & Adelman, R. D. (1996). Psychosocial factors in older patients' medical encounters. *Research on Aging*, 18(1), 84-102.
- Greene, M. G., & Adelman, R. D. (2003). Physician-older patient communication about cancer. *Patient Education and Counseling*, 50(1), 55-60.
- Greene, M. G., Adelman, R. D., Friedmann, E., & Charon, R. (1994a). Older patient satisfaction with communication during an initial medical encounter. *Social Science & Medicine*, 38(9), 1279-1288.

- Greene, M. G., Majerovitz, S. D., Adelman, R. D., & Rizzo, C. (1994b). The effects of the presence of a third person on the physician-older patient medical interview. *Journal of the American Geriatrics Society*, 42(4), 413-419.
- Griffin, A. M., Butow, P. N., Coates, A. S., Childs, A. M., Ellis, P. M., Dunn, S. M., & Tattersall, M. H. (1996). On the receiving end. V: Patient perceptions of the side effects of cancer chemotherapy in 1993. *Annals of Oncology*, 7(2), 189-195.
- Gross, J. J., Carstensen, L. L., Pasupathi, M., Tsai, J., Skorpen, C. G., & Hsu, A. Y. C. (1997). Emotion and aging: Experience, expression, and control. *Psychology and Aging*, 12(4), 590-599.

H

- Hack, T. F., Degner, L. F., & Parker, P. A. (2005). The communication goals and needs of cancer patients: a review. *Psycho-Oncology*, 14(10), 831-845; discussion 846-837.
- Hack, T. F., Pickles, T., Bultz, B. D., Ruether, J. D., & Degner, L. F. (2007). Impact of providing audiotapes of primary treatment consultations to men with prostate cancer: a multi-site, randomized, controlled trial. *Psycho-Oncology*, 16(6), 543-552.
- Hagerty, R. G., Butow, P. N., Ellis, P. M., Dimitry, S., & Tattersall, M. H. N. (2005). Communicating prognosis in cancer care: a systematic review of the literature. *Annals of Oncology*, 16(7), 1005-1053.
- Haley, W. E. (2003). The costs of family caregiving: implications for geriatric oncology. *Critical Reviews in Oncology/Hematology*, 48(2), 151-158.
- Hall, J. A., Irish, J. T., Roter, D. L., Ehrlich, C. M., & Miller, L. H. (1994). Satisfaction, gender, and communication in medical visits. *Medical Care*, 32(12), 1216-1231.
- Hanoch, Y., & Vitouch, O. (2004). When less is more: Information, emotional arousal and the ecological reframing of the Yerkes-Dodson law. *Theory & Psychology*, 14(4), 427-452.
- Hanoch, Y., Wood, S., & Rice, T. (2007). Bounded rationality, emotions and older adult decision making: Not so fast and yet so frugal. *Human Development*, 50(6), 333-358.
- Harden, J. (2005). Developmental life stage and couples' experiences with prostate cancer: a review of the literature. *Cancer Nursing*, 28(2), 85-98.
- Harden, J., Schafenacker, A., Northouse, L., Mood, D., Smith, D., Pienta, K., Hussain, M., & Baranowski, K. (2002). Couples' experiences with prostate cancer: focus group research. *Oncology Nursing Forum*, 29(4), 701-709.
- Harrington, J., Noble, L. M., & Newman, S. P. (2004). Improving patients' communication with doctors: a systematic review of intervention studies. *Patient Education and Counseling*, 52(1), 7-16.
- Hasselkus, B. R. (1992). Physician and family caregiver in the medical setting - negotiation of care. *Journal of Aging Studies*, 6(1), 67-80.
- Hayes, A., & Buffum, M. (2001). Educating patients after conscious sedation for gastrointestinal procedures. *Gastroenterology Nursing*, 24(2), 54-57.

- Heaven, B., Murtagh, M., Rapley, T., May, C., Graham, R., Kaner, E., & Thomson, R. (2006a). Patients or research subjects? A qualitative study of participation in a randomised controlled trial of a complex intervention. *Patient Education and Counseling*, 62(2), 260-270.
- Heaven, C., Clegg, J., & Maguire, P. (2006b). Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. *Patient Education and Counseling*, 60(3), 313-325.
- Heaven, C., & Green, C. (2001). Medical Interview Aural Rating Scale. Psychological Medicine Group, Christie Hospital, Stanley House, Manchester.
- Henry, D. H., Viswanathan, H. N., Elkin, E. P., Traina, S., Wade, S., & Cella, D. (2008). Symptoms and treatment burden associated with cancer treatment: results from a cross-sectional national survey in the U.S. *Support Care Cancer*, 16(7), 791-801.
- Hess, T. M. (2005). Memory and aging in context. *Psychological Bulletin*, 131(3), 383-406.
- Howlader, M. H., Dhanji, A. R., Uppal, R., Magee, P., Wood, A. J., & Anyanwu, A. C. (2004). Patients' views of the consent process for adult cardiac surgery: questionnaire survey. *Scandinavian Cardiovascular Journal*, 38(6), 363-368.
- Hox, J. (1995). *Applied Multilevel Analysis* 2nd edn. Amsterdam: TT Publications
- Hox, J. (2002). *Multilevel analysis: Techniques and applications*. Mahwah, NJ: Erlbaum.
- Hurria, A., Rosen, C., Hudis, C., Zuckerman, E., Panageas, K. S., Lachs, M. S., Witmer, M., van Gorp, W. G., Fournier, M., D'Andrea, G., Moasser, M., Dang, C., Van Poznak, C., & Holland, J. (2006). Cognitive function of older patients receiving adjuvant chemotherapy for breast cancer: a pilot prospective longitudinal study. *Journal of the American Geriatrics Society*, 54(6), 925-931.
- Hutchins, L. F., Unger, J. M., Crowley, J. J., Coltman, C. A., Jr., & Albain, K. S. (1999). Underrepresentation of patients 65 years of age or older in cancer-treatment trials. *The New England Journal of Medicine*, 341(27), 2061-2067.

I

- Iconomou, G., Viha, A., Koutras, A., Vagenakis, A. G., & Kalofonos, H. P. (2002). Information needs and awareness of diagnosis in patients with cancer receiving chemotherapy: a report from Greece. *Palliative Medicine*, 16(4), 315-321.
- Ingram, R. E. (1984). Information processing and feedback: Effects of mood and information favorability on the cognitive processing of personally relevant information. *Cognitive Therapy and Research*, 8(4), 371-386.
- Insel, K., Morrow, D., Brewer, B., & Figueredo, A. (2006). Executive function, working memory, and medication adherence among older adults. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61(2), P102-107.
- Ishikawa, H., Hashimoto, H., Roter, D. L., Yamazaki, Y., Takayama, T., & Yano, E. (2005a). Patient contribution to the medical dialogue and perceived patient-centeredness - An observational study in Japanese geriatric consultations. *Journal of General Internal Medicine*, 20(10), 906-910.

Ishikawa, H., Roter, D. L., Yamazaki, Y., & Takayama, T. (2005b). Physician-elderly patient-companion communication and roles of companions in Japanese geriatric encounters. *Social Science & Medicine*, 60(10), 2307-2320.

J

Jacobsen, P. B., & Jim, H. S. (2008). Psychosocial interventions for anxiety and depression in adult cancer patients: achievements and challenges. *CA: A Cancer Journal for Clinicians*, 58(4), 214-230.

Jahraus, D., Sokolosky, S., Thurston, N., & Guo, D. (2002). Evaluation of an education program for patients with breast cancer receiving radiation therapy. *Cancer Nursing*, 25(4), 266-275.

James, W. (1890). *The principles of psychology*, vols. 1 & 2. New York: Holt.

Jansen, J., Butow, P. N., van Weert, J. C., van Dulmen, S., Devine, R. J., Heeren, T. J., Bensing, J. M., Tattersall, M. H. (2008a). Does age really matter? Recall of information presented to newly referred patients with cancer. *Journal of Clinical Oncology*, 26(33), 5450-5457.

Jansen, J., van Weert, J., van der Meulen, N., van Dulmen, S., Heeren, T., & Bensing, J. (2008b). Recall in older cancer patients: measuring memory for medical information. *Gerontologist*, 48(2), 149-157.

Jansen, J., van Weert, J., van Dulmen, S., Heeren, T., & Bensing, J. (2007). Patient education about treatment in cancer care: an overview of the literature on older patients' needs. *Cancer Nursing*, 30(4), 251-260.

Jefford, M., & Tattersall, M. H. N. (2002). Informing and involving cancer patients in their own care. *Lancet Oncology*, 3(10), 629-637.

Jenkins, V., Fallowfield, L., & Saul, J. (2001). Information needs of patients with cancer: results from a large study in UK cancer centres. *British Journal of Cancer*, 84(1), 48-51.

Johansson, N. O., Andersson, J., & Ronnberg, J. (2005). Compensating strategies in collaborative remembering in very old couples. *Scandinavian Journal of Psychology*, 46(4), 349-359.

K

Kempen, G. I., Meier, A. J., Bouwens, S. F., van Deursen, J., & Verhey, F. R. (2007). [The psychometric properties of the Dutch version of the Telephone Interview Cognitive Status (TICS)]. *Tijdschrift voor Gerontologie en Geriatrie*, 38(1), 38-45.

Kenny, D. A. (1996). Models of Non-Independence in Dyadic Research. *Journal of Social and Personal Relationships*, 13(2), 279-294.

Kenny, D. A., Mannetti, L., Pierro, A., Livi, S., & Kashy, D. A. (2002). The statistical analysis of data from small groups. *Journal of Personality and Social Psychology*, 83(1), 126-137.

- Kessels, R. P. C. (2003). Patients' memory for medical information. *Journal of the Royal Society of Medicine*, 96(5), 219-222.
- Kim, Y. M., Kols, A., Prammawat, S., & Rinehart, W. (2005). Sequence analysis: Responsiveness of doctors to patient cues during family planning consultations in Mexico. *Patient Education and Counseling*, 58(1), 114-117.
- Kiviniemi, M. T., & Rothman, A. J. (2006). Selective memory biases in individuals' memory for health-related information and behavior recommendations. *Psychology and Health*, 21(2), 247.
- Knowles, G., Tierney, A., Jodrell, D., & Cull, A. (1999). The perceived information needs of patients receiving adjuvant chemotherapy for surgically resected colorectal cancer... including commentary by Bailey C and Worster B. *European Journal of Oncology Nursing*, 3(4), 208-222.
- Kruglanski, A. W., Chen, X., Pierro, A., Mannetti, L., Erb, H. P., & Spiegel, S. (2006). Persuasion According to the Unimodel: Implications for Cancer Communication. *Journal of Communication*, 56(s1), 105-122.
- Krupat, E., Rosenkranz, S. L., Yeager, C. M., Barnard, K., Putnam, S. M., & Inui, T. S. (2000). The practice orientations of physicians and patients: the effect of doctor-patient congruence on satisfaction. *Patient Education and Counseling*, 39(1), 49-59.
- Kumana, C. R., Ma, J. T., Kung, A., Kou, M., & Lauder, I. (1988). An assessment of drug information sheets for diabetic patients: only active involvement by patients is helpful. *Diabetes Research and Clinical Practice*, 5(3), 225-231.

L

- Labrecque, M. S., Blanchard, C. G., Ruckdeschel, J. C., & Blanchard, E. B. (1991). The impact of family presence on the physician-cancer patient interaction. *Social Science and Medicine*, 33(11), 1253-1261.
- Lagarde, S. M., Franssen, S. J., van Werven, J. R., Smets, E. M., Tran, T. C., Tilanus, H. W., Plukker, J. T., de Haes, J. C., & van Lanschot, J. J. (2008). Patient preferences for the disclosure of prognosis after esophagectomy for cancer with curative intent. *Annals of Surgical Oncology*, 15(11), 3289-3298.
- Lavelle-Jones, C., Byrne, D. J., Rice, P., & Cuschieri, A. (1993). Factors affecting quality of informed consent. *British Medical Journal*, 306(6882), 885-890.
- Leighl, N., Gattellari, M., Butow, P., Brown, R., & Tattersall, M. H. N. (2001). Discussing adjuvant cancer therapy. *Journal of Clinical Oncology*, 19(6), 1768-1778.
- Lewis, J. H., Kilgore, M. L., Goldman, D. P., Trimble, E. L., Kaplan, R., Montello, M. J., Housman, M. G., & Escarce, J. J. (2003). Participation of patients 65 years of age or older in cancer clinical trials. *Journal of Clinical Oncology*, 21(7), 1383-1389.
- Ley, P. (1979). Memory for medical information. *British Journal of Social and Clinical Psychology*, 18, 245-256.
- Ley, P. (1982a). Satisfaction, compliance and communication. *British Journal of Clinical Psychology*, 21(Pt 4), 241-254.

- Ley, P. (1982b). Understanding, memory, satisfaction and compliance. *British Journal of Clinical Psychology*, 21, 241-254.
- Ley, P. (1988). Communicating with patients: improving communication, satisfaction and compliance (Vol. 4). London: Chapman and Hall.
- Liang, W. H., Burnett, C. B., Rowland, J. H., Meropol, N. J., Eggert, L., Hwang, Y. T., Silliman, R. A., Weeks, J. C., & Mandelblatt, J. S. (2002). Communication between physicians and older women with localized breast cancer: implications for treatment and patient satisfaction. *Journal of Clinical Oncology*, 20(4), 1008-1016.
- Lichtman, S. M., Balducci, L., & Aapro, M. (2007). Geriatric oncology: a field coming of age. *Journal of Clinical Oncology*, 25(14), 1821-1823.
- Light, L. L. (1991). Memory and aging: four hypotheses in search of data. *Annual Reviews of Psychology*, 42, 333-376.
- Lindop, E., & Cannon, S. (2001). Evaluating the self-assessed support needs of women with breast cancer. *Journal of Advanced Nursing*, 34(6), 760-771.
- Lockenhoff, C. E., & Carstensen, L. L. (2004). Socioemotional selectivity theory, aging, and health: the increasingly delicate balance between regulating emotions and making tough choices. *Journal of Personality*, 72(6), 1395-1424.
- Logan, P. D., Schwab, R. A., Salomone, J. A., 3rd, & Watson, W. A. (1996). Patient understanding of emergency department discharge instructions. *Southern Medical Journal*, 89(8), 770-774.
- Love, R. R., Leventhal, H., Easterling, D. V., & Nerenz, D. R. (1989). Side effects and emotional distress during cancer chemotherapy. *Cancer*, 63(3), 604-612.
- Luker, K. A., Beaver, K., Leinster, S. J., Owens, R. G., Degner, L. F., & Sloan, J. A. (1995). The information needs of women newly diagnosed with breast cancer. *Journal of Advanced Nursing*, 22(1), 134-141.

M

- Maibach, E. W., & Cotton, D. (Eds.). (1995). Moving people to behavior change: A staged social cognitive approach to message design. Thousand Oaks, CA: Sage.
- Martinez, M. E. (1999). Cognition and the question of test item format. *Educational Psychologist*, 34(4), 207-218.
- Mather, M., & Carstensen, L. L. (2005). Aging and motivated cognition: the positivity effect in attention and memory. *Trends in Cognitive Science*, 9(10), 496-502.
- Mauksch, L. B., Dugdale, D. C., Dodson, S., & Epstein, R. (2008). Relationship, communication, and efficiency in the medical encounter: creating a clinical model from a literature review. *Archives of Internal Medicine*, 168(13), 1387-1395.
- McGuire, L. C. (1996). Remembering what the doctor said: Organization and adults' memory for medical information. *Experimental Aging Research*, 22(4), 403-428.
- McIlfatrick, S., Sullivan, K., McKenna, H., & Parahoo, K. (2007). Patients' experiences of having chemotherapy in a day hospital setting. *Journal of Advanced Nursing*, 59(3), 264-273.

- McJannett, M., Butow, P., Tattersall, M. H., & Thompson, J. F. (2003). Asking questions can help: development of a question prompt list for cancer patients seeing a surgeon. *European Journal of Cancer Prevention*, 12(5), 397-405.
- Merckaert, I., Libert, Y., Delvaux, N., & Razavi, D. (2005). Breast cancer: communication with a breast cancer patient and a relative. *Annals of Oncology*, 16, 209-212.
- Meredith, C., Symonds, P., Webster, L., Lamont, D., Pyper, E., Gillis, C. R., & Fallowfield, L. (1996). Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *British Medical Journal*, 313(7059), 724-726.
- Messick, S. (1995). Validity of Psychological-Assessment - Validation of Inferences from Persons Responses and Performances as Scientific Inquiry into Score Meaning. *American Psychologist*, 50(9), 741-749.
- Meudell, P. R., Hitch, G. J., & Kirby, P. (1992). Are 2 heads better than one - Experimental investigations of the social facilitation of memory. *Applied Cognitive Psychology*, 6(6), 525-543.
- Michie, S., French, D., Allanson, A., Bobrow, M., & Marteau, T. M. (1997). Information recall in genetic counselling: A pilot study of its assessment. *Patient Education and Counseling*, 32, 93-100.
- Middleton, S., Gattellari, M., Harris, J. P., & Ward, J. E. (2006). Assessing surgeons' disclosure of risk information before carotid endarterectomy. *ANZ Journal of Surgery*, 76(7), 618-624.
- Miller, G. A. (1956). The magical number seven plus or minus two: some limits on our capacity for processing information. *Psychological Review*, 63(2), 81-97.
- Miller, M. E., Rejeski, W. J., Reboussin, B. A., Ten Have, T. R., & Ettinger, W. H. (2000). Physical activity, functional limitations, and disability in older adults. *Journal of the American Geriatrics Society*, 48(10), 1264-1272.
- Mitchell, T. (2007). The social and emotional toll of chemotherapy - patients' perspectives. *European Journal of Cancer Care (Engl)*, 16(1), 39-47.
- Molassiotis, A. (2004). Challenges and opportunities when using oral chemotherapy in the home setting: the example of capecitabine (Xeloda(R)). *European Journal of Oncology Nursing*, 8(Supplement 1), S1-S3.
- Moosdijk, B. M., & Postma-Schuit, F. C. E. Evaluatierapport implementatie Behandelwijzer Chemotherapie en Cytostatica Informatiekaarten in de IKA-regio [Evaluation of the implementation of the Treatment Guide to Chemotherapy and Cytostatics Information Cards in the IKA-region]. IKA, Amsterdam, 2000.
- Morrow, D., Leirer, V. O., Carver, L. M., Tanke, E. D., & McNally, A. D. (1999). Repetition improves older and younger adult memory for automated appointment messages. *Human Factors*, 41(2), 194-204.
- Morrow, D. G., Weiner, M., Young, J., Steinley, D., Deer, M., & Murray, M. D. (2005). Improving medication knowledge among older adults with heart failure: a patient-centered approach to instruction design. *Gerontologist*, 45(4), 545-552.

- Mulders, M., Vingerhoets, A., & Breed, W. (2008). The impact of cancer and chemotherapy: perceptual similarities and differences between cancer patients, nurses and physicians. *European Journal of Oncology Nursing*, 12(2), 97-102.
- Murdoch, M., & Wilt, T. J. (1997). Cholesterol awareness after case-finding: do patients really know their cholesterol numbers? *American Journal of Preventive Medicine*, 13(4), 284-289.
- Muthu, K. D., Symonds, R. P., Sundar, S., Ibrahim, K., Savelyich, B. S., & Miller, E. (2004). Information needs of Asian and White British cancer patients and their families in Leicestershire: a cross-sectional survey. *British Journal of Cancer*, 90(8), 1474-1478.
- Myers, L., & Derakshan, N. (2004). To forget or not to forget: What do repressors forget and when do they forget? *Cognition & Emotion*, 18(4), 495-511.

N

- Nerenz, D. R., Love, R. R., Leventhal, H., & Easterling, D. V. (1986). Psychosocial consequences of cancer chemotherapy for elderly patients. *Health Services Research*, 20(6 Pt 2), 961-976.
- Neumann, M., Wirtz, M., Bollschweiler, E., Mercer, S. W., Warm, M., Wolf, J., & Pfaff, H. (2007). Determinants and patient-reported long-term outcomes of physician empathy in oncology: a structural equation modelling approach. *Patient Education and Counseling*, 69(1-3), 63-75.
- Neupert, S. D., & McDonald-Miszczak, L. (2004). Younger and older adults' delayed recall of medication instructions: The role of cognitive and metacognitive predictors. *Aging Neuropsychology and Cognition*, 11(4), 428-442.
- Nussbaum, J. F., & Baringer, D. K. (2000). Message Production Across the Life Span: Communication and Aging. *Communication Theory*, 10(2), 200-209.
- Nussbaum, J. F., Baringer, O., & Kundrat, A. (2003). Health, communication, and aging: cancer and older adults. *Health Communication*, 15(2), 185-192.

O

- Olver, I. N., Turrell, S. J., Olszewski, N. A., & Willson, K. J. (1995). Impact of an information and consent form on patients having chemotherapy. *Medical Journal of Australia*, 162(2), 82-83.
- Ong, L. M., Visser, M. R., Lammes, F. B., & de Haes, J. C. (2000). Doctor-patient communication and cancer patients' quality of life and satisfaction. *Patient Education and Counseling*, 41(2), 145-156.
- Ong, L. M. L., Haes, J. C. J. M. d., Hoos, A. M., & Lammes, F. B. (1995). Doctor-patient communication: a review of the literature. *Social Science & Medicine*, 40(7), 903-918.

P

- Pasetto, L. M., Falci, C., Compostella, A., Sinigaglia, G., Rossi, E., & Monfardini, S. (2007). Quality of life in elderly cancer patients. *European Journal of Cancer*, 43(10), 1508-1513.
- Paterniti, S., Verdier-Taillefer, M. H., Dufouil, C., & Alperovitch, A. (2002). Depressive symptoms and cognitive decline in elderly people - Longitudinal study. *British Journal of Psychiatry*, 181, 406-410.
- Pesudovs, K., Luscombe, C. K., & Coster, D. J. (2006). Recall from informed consent counselling for cataract surgery. *American Journal of Law and Medicine*, 13(4), 496-504.
- Peters, E., Lipkus, I., & Diefenbach, M. A. (2006). The functions of affect in health communications and in the construction of health preferences. *Journal of Communication*, 56, S140-S162.
- Petty, R. E., Goldman, R., & Cacioppo, J. T. (1981). Personal involvement as a determinant of argument-based persuasion. *Journal of Personality and Social Psychology*, 41(5), 847-855.
- Petty, R. E., Wegener, D. T., & Fabrigar, L. R. (1997). Attitudes and attitude change. *Annual Review of Psychology*, 48, 609-647.
- Pickersgill, M. J., & Owen, A. (1992). Mood-states, recall and subjective comprehensibility of medical information in nonpatient volunteers. *Personality and Individual Differences*, 13(12), 1299-1305.
- Pinquart, M., & Duberstein, P. R. (2004). Information needs and decision-making processes in older cancer patients. *Critical Reviews in Oncology / Hematology*, 51(1), 69-80.
- Posma, E. R., van Weert, J. C., Jansen, J., & Bensing, J. M. (2009). Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*, 8(1), 1.
- Ptacek, J. T., & Eberhardt, T. L. (1996). Breaking bad news. A review of the literature. *The Journal of the American Medical Association*, 276(6), 496-502.

R

- Rasbash, J., Browne, W., Goldstein, H., Yang, M., Plewis, I., & Healy, M. (2000). A user's guide to MLwiN.
- Ream, E., & Richardson, A. (1996). The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature. *European Journal of Cancer Care (Engl)*, 5(3), 132-138.
- Reed, A. E., Mikels, J. A., & Simon, K. I. (2008). Older adults prefer less choice than young adults. *Psychology and Aging*, 23(3), 671-675.
- Repetto, L., & Balducci, L. (2002). A case for geriatric oncology. *Lancet Oncology*, 3(5), 289-297.
- Rimer, B. K., & Kreuter, M. W. (2006). Advancing tailored health communication: A persuasion and message effects perspective. *Journal of Communication*, 56, S184-S201.

- Rimondini, M., Del Piccolo, L., Goss, C., Mazzi, M., Paccaloni, M., & Zimmermann, C. (2006). Communication skills in psychiatry residents - How do they handle patient concerns? An application of sequence analysis to interviews with simulated patients. *Psychotherapy and Psychosomatics*, 75(3), 161-169.
- Rodin, M. B., & Mohile, S. G. (2007). A practical approach to geriatric assessment in oncology. *Journal of Clinical Oncology*, 25(14), 1936-1944.
- Rost, K., & Roter, D. (1987). Predictors of recall of medication regimens and recommendations for life-style change in elderly patients. *Gerontologist*, 27(4), 510-515.
- Rost, K., Roter, D., Bertakis, K., & Quill, T. (1990). Physician-patient familiarity and patient recall of medication changes. The collaborative study group of the SGIM task force on the doctor and patient. *Family Medicine*, 22(6), 453-457.
- Roter, D. L. (2000). The outpatient medical encounter and elderly patients. *Clinics in Geriatric Medicine*, 16(1), 95-107.
- Roter, D. L., Hall, J. A., & Katz, N. R. (1987). Relations between physicians behaviors and analog patients satisfaction, recall, and impressions. *Medical Care*, 25(5), 437-451.
- Rushford, N., Murphy, B. M., Worcester, M. U., Goble, A. J., Higgins, R. O., Le Grande, M. R., Rada, J., & Elliott, P. C. (2007). Recall of information received in hospital by female cardiac patients. *European Journal of Cardiovascular Prevention & Rehabilitation*, 14(3), 463-469.
- Rutten, L. J., Arora, N. K., Bakos, A. D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Education and Counseling*, 57(3), 250-261.

S

- Sahay, T. B., Gray, R. E., & Fitch, M. (2000). A qualitative study of patient perspectives on colorectal cancer. *Cancer Practice: A Multidisciplinary Journal of Cancer Care*, 8(1), 38-44.
- Salthouse, T. A. (1996). The processing-speed theory of adult age differences in cognition. *Psychological Review*, 103(3), 403-428.
- Sand, K., Loge, J. H., & Kaasa, S. (2008). The understanding of informed consent information: definitions in empirical studies. Paper presented at the EACH, International Conference on Communication in Healthcare.
- Sanderman, R., Coyne, J. C., & Ranchor, A. V. (2006). Age: Nuisance variable to be eliminated with statistical control or important concern? *Patient Education and Counseling*, 61(3), 315-316.
- Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer*, 88(1), 226-237.
- Satariano, W. A., & Silliman, R. A. (2003). Comorbidity: implications for research and practice in geriatric oncology. *Critical Reviews in Oncology / Hematology*, 48(2), 239-248.

- Schilling, L. M., Scatena, L., Steiner, J. F., Albertson, G. A., Lin, C. T., Cyran, L., Ware, L., & Anderson, R. J. (2002). The third person in the room: Frequency, role, and influence of companions during primary care medical encounters. *Journal of Family Practice*, 51(8), 685-690.
- Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Daher, C., Leong-Grotz, K., Castro, C., & Bindman, A. B. (2003). Closing the loop: physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*, 163(1), 83-90.
- Schmid Mast, M., Kindlimann, A., & Langewitz, W. (2005). Recipients' perspective on breaking bad news: how you put it really makes a difference. *Patient Education and Counseling*, 58(3), 244-251.
- Schofield, P., Jefford, M., Carey, M., Thomson, K., Evans, M., Baravelli, C., & Aranda, S. (2008). Preparing patients for threatening medical treatments: effects of a chemotherapy educational DVD on anxiety, unmet needs, and self-efficacy. *Supportive Care in Cancer*, 16(1), 37-45.
- Schofield, P. E., Butow, P. N., Thompson, J. F., Tattersall, M. H. N., Beeney, L. J., & Dunn, S. M. (2003). Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology*, 14(1), 48-56.
- Schuermans, H., Steverink, N., Lindenberg, S., Frieswijk, N., & Slaets, J. P. (2004). Old or frail: what tells us more? *Journals of Gerontology Series A-Biological Sciences and Medical Sciences*, 59(9), M962-M965.
- SEER Cancer Statistics Review, 1975-2004 (2007). from http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.
- Sheard, T., & Maguire, P. (1999). The effect of psychological interventions on anxiety and depression in cancer patients: results of two meta-analyses. *British Journal of Cancer*, 80(11), 1770-1780.
- Shields, C. G., Epstein, R. M., Fiscella, K., Franks, P., McCann, R., McCormick, K., & Mallinger, J. B. (2005). Influence of accompanied encounters on patient-centeredness with older patients. *Journal of the American Board of Family Practice*, 18(5), 344-354.
- Silberman, J., Tentler, A., Ramgopal, R., & Epstein, R. M. (2008). Recall-promoting physician behaviors in primary care. *Journal of General Internal Medicine*, 23(9), 1487-1490.
- Siminoff, L. A., Graham, G. C., & Gordon, N. H. (2006). Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Education and Counseling*, 62(3), 355-360.
- Siminoff, L. A., Ravdin, P., Colabianchi, N., & Sturm, C. M. (2000). Doctor-patient communication patterns in breast cancer adjuvant therapy discussions. *Health Expectations*, 3(1), 26-36.
- Snelgrove, S. (2006). A consideration of memory in relation to information giving. *Nursing Times*, 102(9), 26-28.
- Spielberger, C. D. (1983). State-Trait Anxiety Inventory (Selfevaluation Questionnaire). Palo Alto University, California: Consulting Psychologists Press.

- Stanley, M. A., Novy, D. M., Bourland, S. L., Beck, J. G., & Averill, P. M. (2001). Assessing older adults with generalized anxiety: a replication and extension. *Behavioral Research and Therapy*, 39(2), 221-235.
- Steginga, S. K., Occhipinti, S., Dunn, J., Gardiner, R. A., Heathcote, P., & Yaxley, J. (2001). The supportive care needs of men with prostate cancer (2000). *Psycho-Oncology*, 10(1), 66-75.
- Stewart, D. E., Wong, F., Cheung, A. M., Dancey, J., Meana, M., Cameron, J. I., McAndrews, M. P., Bunston, T., Murphy, J., & Rosen, B. (2000a). Information needs and decisional preferences among women with ovarian cancer. *Gynecological Oncology*, 77(3), 357-361.
- Stewart, M., Meredith, L., Brown, J. B., & Galajda, J. (2000b). The influence of older patient-physician communication on health and health-related outcomes. *Clinics in Geriatric Medicine*, 16(1), 25-36, vii-viii.
- Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal*, 152(9), 1423-1433.
- Street, R. L., & Gordon, H. S. (2008). Companion participation in cancer consultations. *Psycho-Oncology*, 17(3), 244-251.
- Street, R. L., Gordon, H. S., Ward, M. M., Krupat, E., & Kravitz, R. L. (2005). Patient participation in medical consultations - Why some patients are more involved than others. *Medical Care*, 43(10), 960-969.
- Street, R. L., Jr. (1991). Information-giving in medical consultations: the influence of patients' communicative styles and personal characteristics. *Social Science & Medicine*, 32(5), 541-548.
- Street, R. L., & Millay, B. (2001). Analyzing patient participation in medical encounters. *Health Communication*, 13(1), 61-73.

T

- Tallarico, M., Figueiredo, M., Goodman, M., Kreling, B., & Mandelblatt, J. (2005). Psychosocial determinants and outcomes of chemotherapy in older women with breast cancer: What do we know? What do we need to know? *Cancer Journal*, 11(6), 518-528.
- Timmermans, E. M. (2007). Patient participation in radiation oncology, Radboud Universiteit, Nijmegen.
- Timmermans, L. M., van der Maazen, R. W., van Spaendonck, K. P., Leer, J. W., & Kraaimaat, F. W. (2006). Enhancing patient participation by training radiation oncologists. *Patient Education and Counseling*, 63(1-2), 55-63.
- Tishelman, C. (1993). Who cares? Patients' descriptions of age-related aspects of cancer and care in Stockholm. *Cancer Nursing*, 16(4), 270-282.
- Tromp, F., van Dulmen, S., & van Weert, J. (2004). Interdisciplinary preoperative patient education in cardiac surgery. *Journal of Advanced Nursing*, 47(2), 212-222.

U

- Uitterhoeve, R., de Leeuw, J., Bensing, J., Heaven, C., Borm, G., Demulder, P., & van Achterberg, T. (2007). Cue-responding behaviours of oncology nurses in video-simulated interviews. *Journal of Advanced Nursing*, 61(1), 71-80.
- Uitterhoeve, R., Duijnhouwer, E., Ambaum, B., & van Achterberg, T. (2003). Turning toward the psychosocial domain of oncology nursing: a main problem analysis in the Netherlands. *Cancer Nursing*, 26(1), 18-27.

V

- Valentijn, S. A., van Boxtel, M. P., van Hooren, S. A., Bosma, H., Beckers, H. J., Ponds, R. W., & Jolles, J. (2005). Change in sensory functioning predicts change in cognitive functioning: results from a 6-year follow-up in the maastricht aging study. *Journal of the American Geriatrics Society*, 53(3), 374-380.
- Valentijn, S. A. M., Hill, R. D., Van Hooren, S. A. H., Bosma, H., Van Boxtel, M. P. J., Jolles, J., & Ponds, R. W. H. M (2006). Memory self-efficacy predicts memory performance: Results from a 6-year follow-up study. *Psychology and Aging*, 21(1), 165-172.
- van den Brink-Muinen, A., Verhaak, P. F., Bensing, J. M., Bahrs, O., Deveugele, M., Gask, L., Mead, N., Leiva-Fernandez, F., Perez, A., Messerli, V., Oppizzi, L., & Peltenburg, M. (2003). Communication in general practice: differences between European countries. *Family Practice*, 20(4), 478-485.
- van der Meulen, N., Jansen, J., van Dulmen, S., Bensing, J., & van Weert, J. (2008). Interventions to improve recall of medical information in cancer patients: a systematic review of the literature. *Psycho-Oncology*, 17(9), 857-868.
- van der Ploeg, H. M., Defares, P. B., & Spielberger, C. D. (1980). Handleiding bij de Zelfbeoordelings Vragenlijst (ZBV) [Manual of the Dutch version of the State Trait Anxiety Inventory]. Lisse: Swets and Zeitlinger.
- van Weert, J., van Dulmen, S., Bar, P., & Venus, E. (2003). Interdisciplinary preoperative patient education in cardiac surgery. *Patient Education and Counseling*, 49(2), 105-114.
- van Weert, J. C., Jansen, J., de Best, A., Posma, E. R., Noordman, J., de Groot, J., van der Meulen, N., & van Dulmen, A. M. (2008a). In gesprek over chemotherapie deel 1. Handvatten voor patiëntgerichte voorlichting aan ouderen met kanker: NIVEL.
- van Weert, J. C., Jansen, J., de Best, A., Posma, E. R., Noordman, J., de Groot, J., van der Meulen, N., & van Dulmen, A. M. (2008b). In gesprek over chemotherapie deel 2. Een video-observatie onderzoek naar patiëntgerichtheid en recall van informatie tijdens verpleegkundige voorlichting aan ouderen met kanker: NIVEL.
- van Weert, J. C., van Dulmen, A. M., Spreeuwenberg, P. M., Ribbe, M. W., & Bensing, J. M. (2005). Effects of snoezelen, integrated in 24 h dementia care, on nurse-patient communication during morning care. *Patient Education and Counseling*, 58(3), 312-326.

- van Weert, J. C. M., Jansen, J., de Bruijn G. J., Noordman J., van Dulmen A. M., & Bensing J.M. (submitted). QUOTEchemo: A patient-centered instrument to measure quality of care through the patient's eyes preceding chemotherapy treatment.
- van Zuuren, F. J., de Groot, K. I., Mulder, N. L., & Muris, P. (1996). Coping with medical threat: An evaluation of the Threatening Medical Situations Inventory (TMSI). *Personality and Individual Differences*, Vol 21(1) Jul 1996, 21-31.
- van Zuuren, F. J., & Wolfs, H. M. (1991). Styles of information seeking under threat: Personal and situational aspects of monitoring and blunting. *Personality and Individual Differences*, 12(2), 141-149.
- Verhaeghen, P., Borchelt, M., & Smith, J. (2003). Relation Between Cardiovascular and Metabolic Disease and Cognition in Very Old Age: Cross-Sectional and Longitudinal Findings From the Berlin Aging Study. *Health Psychology*, 22(6), 559-569.
- Verity, R., Wiseman, T., Ream, E., Teasdale, E., & Richardson, A. (2008). Exploring the work of nurses who administer chemotherapy. *European Journal of Oncology Nursing*, 12(3), 244-252.
- Vos, M. S., & de Haes, J. C. (2007). Denial in cancer patients, an explorative review. *Psycho-Oncology*, 16(1), 12-25.

W

- Weiss, C. O., Boyd, C. M., Yu, Q., Wolff, J. L., & Leff, B. (2007). Patterns of prevalent major chronic disease among older adults in the United States. *Journal of the American Medical Association*, 298(10), 1160-1162.
- Wessel, I., van der, K. P., & Merckelbach, H. (2000). Differential recall of central and peripheral details of emotional slides is not a stable phenomenon. *Memory*, 8(2), 95-109.
- Wolff, J. L., & Roter, D. L. (2008). Hidden in plain sight - Medical visit companions as a resource for vulnerable older adults. *Archives of Internal Medicine*, 168(13), 1409-1415.
- Wong, F., Stewart, D. E., Dancey, J., Meana, M., McAndrews, M. P., Bunston, T., & Cheung, A. M. (2000). Men with prostate cancer: influence of psychological factors on informational needs and decision making. *Journal of Psychosomatic Research*, 49(1), 13-19.

Y

- Yancik, R. (2005). Population aging and cancer: A cross-national concern. *Cancer Journal*, 11(6), 437-441.
- Yancik, R., & Ries, L. A. (2004). Cancer in older persons: an international issue in an aging world. *Seminars in Oncology*, 31(2), 128-136.
- Yardley, S. J., Davis, C. L., & Sheldon, F. (2001). Receiving a diagnosis of lung cancer: patients' interpretations, perceptions and perspectives. *Palliative Medicine*, 15(5), 379-386.

- Yee, K. W., Pater, J. L., Pho, L., Zee, B., & Siu, L. L. (2003). Enrollment of older patients in cancer treatment trials in Canada: why is age a barrier? *Journal of Clinical Oncology*, 21(8), 1618-1623.
- Young, A. M., & Kerr, D. J. (2001). Home delivery: chemotherapy and pizza? *British Medical Journal*, 322(7290), 809-810.

Z

- Zandbelt, L. C. (2008). Cancer patients' considerations concerning their information need. Paper presented at the EACH, International Conference on Communication In Healthcare.
- Zandbelt, L. C., Smets, E. M. A., Oort, F. J., & de Haes, H. (2005). Coding patient-centred behaviour in the medical encounter. *Social Science & Medicine*, 61(3), 661-671.
- Zimmermann, C., Del Piccolo, L., & Finset, A. (2007). Cues and concerns by patients in medical consultations: a literature review. *Psychological Bulletin*, 133(3), 438-463.

Samenvatting

De invloed van communicatie op het reproduceren van informatie door oudere patiënten met kanker

Tijdens oncologische consulten worden patiënten geconfronteerd met veel, ingewikkelde, en vaak emotioneel beladen informatie die lastig is om te begrijpen en te onthouden. Het is dan ook niet verrassend dat verschillende studies hebben aangetoond dat patiënten het grootste gedeelte van de informatie die wordt besproken tijdens consulten weer vergeten. Een belangrijk doel van communicatie is dat patiënten zoveel mogelijk informatie begrijpen, onthouden en kunnen reproduceren ('recall'). 'Recall' van informatie is een voorwaarde voor therapietrouw en daardoor indirect van invloed op zelfmanagement en herstel. Aangenomen wordt dat ouderen gemiddeld genomen minder informatie kunnen reproduceren dan jongeren, als gevolg van cognitieve achteruitgang. 'Recall' van informatie onder ouderen met kanker is echter nog nooit gericht onderzocht. Meer dan 55% van de patiënten met kanker in Nederland is 65 jaar of ouder. Omdat de populatie vergrijst en de kankerincidentie toeneemt met leeftijd, zijn er steeds meer ouderen met kanker.

Dit proefschrift gaat over factoren die van belang zijn in communicatie met oudere patiënten met kanker (≥ 65 jaar), waarbij we ons specifiek hebben gericht op hoe deze factoren het reproduceren van informatie beïnvloeden. De achtergrond van dit proefschrift is deels gebaseerd op het Selectieve Optimalisatie met Compensatie model over veroudering (SOC model, Baltes & Baltes, 1990). Kort samengevat gaat dit model er vanuit dat ouder worden gepaard gaat met zowel groei als verlies en dat het voor succesvol ouder worden van belang is dat ouderen hun gedrag aanpassen aan leeftijdsgerelateerde veranderingen. Bijvoorbeeld door selectief te zijn in de doelen die men nastreeft, de bronnen die men nodig heeft om doelen te bereiken te optimaliseren en eventuele verliezen (bijvoorbeeld cognitieve achteruitgang) zoveel mogelijk te compenseren. Het SOC model propageert

een multi-dimensionale benadering voor het bestuderen van verouderingsprocessen. In het eerste hoofdstuk van dit proefschrift wordt een beeld geschetst van verschillende cognitieve, fysieke, psychologische en sociale veranderingen die gepaard gaan met het ouder worden en hun relatie met communicatie en 'recall'. Dit proefschrift bevat de resultaten van drie studies die gerelateerd zijn aan één of meer van de hierboven genoemde thema's.

Onderzoeksbevindingen

Met het toenemen van de leeftijd worden mensen steeds selectiever in de doelen die ze nastreven. Korte termijn doelen gericht op emotioneel welbevinden worden steeds belangrijker, terwijl doelen gericht op de toekomst minder belangrijk worden. Daarnaast bevinden oudere patiënten met kanker zich in een andere levensfase dan jongeren en hebben mogelijk andere ideeën over de ziekte kanker. Onze verwachting was dat oudere patiënten hierdoor andere voorkeuren hebben dan jongere patiënten. In **Hoofdstuk 2** is door middel van een systematische literatuurstudie geïnventariseerd of de behoefte aan informatie en steun die patiënten met kanker rondom (de start van) hun behandeling ervaren, gebonden is aan leeftijd. Eén van de meest interessante bevindingen van de literatuurstudie is dat niet één studie zich specifiek richtte op de voorkeuren en behoeften van oudere patiënten met kanker. We hebben daarom studies meegenomen in het literatuuroverzicht als een deel van de patiënten 65 jaar of ouder was en leeftijdsverschillen, of het uitblijven er van, werden gerapporteerd. De resultaten laten zien dat, hoewel oudere patiënten aangeven geïnformeerd te willen worden over de belangrijkste aspecten van hun ziekte en de behandeling, ze minder geïnteresseerd zijn in het kennen van alle details. Daarnaast hebben oudere patiënten in vergelijking met jongere patiënten minder behoefte aan psychosociale steun en aan steun en informatie op het gebied van seksualiteit en lichaamsbeeld.

Naarmate mensen ouder worden, ervaren ze meer problemen met cognitieve functies. Dat maakt het onthouden van medische informatie moeilijker. Aan de andere kant hebben oudere patiënten meer ervaring met ziek zijn en wordt

aangenomen dat ouderen beter met emoties om kunnen gaan, wat de cognitieve achteruitgang mogelijk kan compenseren. Daarnaast laat recent onderzoek binnen de geriatrische oncologie zien dat niet zozeer de chronologische leeftijd maar factoren zoals functionele, psychologische en fysieke status bepalen welke patiënten met kanker het beste ziekte verloop hebben. In **Hoofdstuk 3** is nagegaan in hoeverre leeftijd de communicatie tussen patiënten en hun radioloog of oncoloog beïnvloedt. Specifiek is onderzocht wat de invloed is van chronologische leeftijd, leeftijdsgerelateerde factoren en communicatie op 'recall'. Om dit doel te bereiken is secundaire data-analyse uitgevoerd op data van een Australische studie. De resultaten van dit onderzoek laten zien dat, in vergelijking met jongere patiënten, oudere patiënten lager opgeleid waren, een slechtere functionele status hadden, vaker een palliatieve in plaats van een curatieve behandeling ondergingen, een slechtere prognose hadden en minder angstig waren. In contrast met de literatuurstudie vonden we geen leeftijdsverschillen in de informatiebehoefte en voorkeuren van patiënten. Onafhankelijk van hun leeftijd wilden de meeste patiënten volledig geïnformeerd worden. Oudere patiënten stelden wel minder vragen dan jongere patiënten. Ook hadden oudere patiënten meer moeite met het reproduceren van medische informatie. Dit effect was alleen aanwezig als de lengte van het consult en de totale hoeveelheid informatie die was besproken in ogenschouw werden genomen. Als de duur van het consult gelijk was en evenveel informatie werd besproken, onthielden oudere patiënten minder dan jongere patiënten. Daarnaast onthielden zowel jongeren als ouderen minder informatie naarmate meer werd besproken in het consult. We vonden ook onverwachte resultaten: prognose was op twee manieren een belangrijke voorspeller van 'recall' van informatie. In de eerste plaats bleek dat hoe slechter de prognose van een patiënt was, des te lager de 'recall'. Patiënten met een geschatte levensverwachting van weken tot maanden of jaren reproduceerden minder dan patiënten met een normale levensverwachting. Ten tweede bleek dat als er uitgebreider werd gesproken over de prognose, patiënten ook minder reproduceerden, ongeacht of hun daadwerkelijke prognose goed of slecht was. Hoewel de relatie tussen prognose en verminderende recall op basis van dit onderzoek niet kan worden verklaard, spelen ontkenning ('denial') en vernauwing van aandacht ('attentional narrowing') mogelijk een rol bij het bespreken van stressvolle informatie. We concludeerden dat de oudste patiënten niet altijd de meest kwetsbare ('frail')

patiënten zijn. Zowel de prognose van een patiënt als de hoeveelheid informatie over de prognose bleken belangrijke voorspellers zijn van informatie 'recall'.

In **Hoofdstuk 4** hebben we een vragenlijst ontwikkeld om de 'recall' te meten van oudere patiënten met kanker na verpleegkundige voorlichting over chemotherapie. Dit was de eerste studie die 'recall' van informatie in verpleegkundige consulten over chemotherapie onderzocht, en er was daarom geen bestaande vragenlijst beschikbaar. De 'recall' vragenlijst bestond uit multiple-choice vragen ('herkenningsvragen'), vragen waarop een kort antwoord kon worden gegeven ('invulvragen') en open vragen ('actieve reproductie'). De vragen hadden betrekking op de behandeling met chemotherapie en adviezen over het omgaan met bijwerkingen. De validiteit van de vragenlijst is getest in een pilot groep van 10 oudere patiënten. De uiteindelijke 'recall' vragenlijst is daarna afgenomen bij 69 patiënten (≥ 65 jaar) die voor de eerste keer chemotherapie kregen. De patiënten vulden de vragenlijst direct na het voorlichtingsgesprek in. Vervolgens zijn de antwoorden vergeleken met de inhoud van het daadwerkelijke gesprek en kon een percentage 'recall' berekend worden. De resultaten laten zien dat er gemiddeld 82 items werden besproken in de voorlichtingsgesprekken. De gemiddelde recall score was 23% voor de open vragen, 68% voor de korte invulvragen en 80% voor de multiple-choice vragen. We concludeerden dat oudere patiënten worden geconfronteerd met een grote hoeveelheid informatie en dat ze moeite hebben deze informatie actief te reproduceren, maar relatief goed zijn in het herkennen ervan.

Adequaat reageren op de emoties en informatiebehoeften die worden geuit door patiënten hangt samen met onder andere hogere tevredenheid en minder psychosociale problemen. In **Hoofdstuk 5** is onderzocht of en hoe signalen van oudere patiënten die wijzen op een onderliggende vraag (informatieele 'cue') of emotie (emotionele 'cue') van invloed zijn op 'recall'. Ook is nagegaan wat de invloed van reacties op deze cues door de verpleegkundige is op 'recall' bij de patiënt. Dit is een belangrijk onderwerp omdat de literatuur laat zien dat in vergelijking met jongere patiënten, oudere patiënten minder snel hun voorkeuren en zorgen uiten, maar tegelijkertijd meer baat hebben bij informatie die aansluit bij hun behoeften en emoties. We verwachtten dat als

verpleegkundigen aandacht hebben voor de cues van de patiënt, patiënten meer onthouden van de voorlichting. De cues en reacties zijn gecodeerd met een aangepaste versie van de Medical Interview Aural Rating Scale (MIARS). De resultaten lieten zien dat het uiten van emotionele noch informationele cues invloed hadden op 'recall'. De manier waarop verpleegkundigen reageerden op informationele cues had ook geen invloed op 'recall'. Echter, 'recall' werd wel beïnvloed door de reacties van verpleegkundigen op emotionele cues van de patiënt. Hoe meer verpleegkundigen reageerden op emotionele cues met een aanmoediging in de vorm van een bevestiging (bijvoorbeeld 'hmm', 'ja', 'oké' of 'ga verder') of door het laten vallen van een functionele stilte, hoe hoger de recall scores van de patiënt. Aan de andere kant bleek dat hoe meer de verpleegkundige afstand nam van de emoties van de patiënt, bijvoorbeeld door niet op de emotionele cue te reageren of in te gaan op feitelijke informatie in plaats van op de emotie, hoe minder de patiënt kon reproduceren.

Zoals aangetoond in Hoofdstuk 3, hebben oudere patiënten tot op bepaalde hoogte meer moeite met het onthouden van medische informatie dan jongere patiënten. Oudere patiënten nemen ook vaker familie of vrienden mee naar het consult. Naasten onthouden mogelijk andere informatie dan de patiënt waardoor ze samen meer onthouden dan de patiënt alleen. Bovendien spelen naasten niet alleen een belangrijke rol in het gesprek met de arts of verpleegkundige, ze zijn vaak ook direct betrokken bij de zorg voor de patiënt, zoals bij het innemen van medicijnen en het omgaan met bijwerkingen. Een naaste die meer informatie onthoudt, is beter in staat om de patiënt op de juiste manier te ondersteunen. In **Hoofdstuk 6** is onderzocht wat de invloed is van de aanwezigheid van een naaste op 'recall' van de patiënt en zijn 'recall' scores van patiënt en naaste met elkaar vergeleken. Zoals we hadden verwacht, onthielden patient-naaste koppels samen meer dan ieder van hen apart (zowel absoluut als relatief). 'Recall' van patiënt en naaste was opgeteld ook hoger dan de 'recall' scores van patiënten die zonder naaste naar het gesprek waren gekomen. Dit was echter alleen het geval voor absolute 'recall' en niet voor proportionele 'recall'. Een mogelijke verklaring voor het feit dat patiënten zonder naasten proportioneel even veel onthielden als de patient-naaste koppels samen is dat verpleegkundigen minder informatie bespraken als de patiënt alleen was en deze gesprekken korter duurden.

Conclusies en aanbevelingen

Op basis van onze studies kunnen we de volgende conclusies trekken en aanbevelingen geven:

Oudere patiënten hebben minder behoefte aan volledige informatie (Hoofdstuk 2) en onthouden minder medische informatie (Hoofdstuk 3) dan jongere patiënten. De verschillen in informatiebehoefte zijn echter gering en andere factoren zoals de prognose van de patiënt spelen een minstens even belangrijke rol als het gaat om 'recall'. Het is daarom belangrijk om oudere patiënten expliciet naar hun informatiebehoefte te vragen, in plaats van informatie voorkeuren te baseren op leeftijd.

Reageren op emotionele signalen van de patiënt door het geven van aanmoedigingen (bijvoorbeeld 'hmm', 'ja' of 'ga verder') heeft een positieve invloed op wat patiënten van het gesprek kunnen reproduceren (Hoofdstuk 5). Daarnaast heeft het bespreken van emotioneel geladen informatie over de prognose een negatief effect op 'recall' (Hoofdstuk 3). Dit betekent dat het in de communicatie met oudere patiënten met kanker belangrijk is om tijdens het geven van informatie alert te zijn op subtiele tekenen van emoties van de patiënt en de patiënt ruimte te geven deze emoties te uiten. In gesprekken waar de vooruitzichten van de patiënt worden besproken, is het van belang na te gaan of andere informatie, bijvoorbeeld over het omgaan met bijwerkingen, nog wel beklijft. Soms kan het beter zijn om te besluiten tijdens het consult vooral aandacht te besteden aan de emotionele reactie van de patiënt en het geven van andere informatie en belangrijke beslissingen, bijvoorbeeld over de behandeling, te bespreken in een apart gesprek. Het is wel belangrijk om dit te doen in overleg met de patiënt.

De aanwezigheid van een partner en of kind(eren) kan de patiënt helpen bij het onthouden van de informatie, aangezien naasten deels andere dingen onthouden dan de patiënt zelf (Hoofdstuk 6). Echter, consulten duren langer als naasten aanwezig zijn en patiënten die alleen naar het consult komen onthouden niet noodzakelijk minder van het gesprek dan patiënten die worden begeleid door vrienden of familie. Dit betekent dat patiënten die graag iemand meenemen naar het consult zeker gestimuleerd moeten worden om dit te

doen. Patiënten die liever alleen naar het gesprek komen hoeven echter niet overtuigd te worden toch iemand mee te nemen.

Patiënten kunnen, ongeacht hun leeftijd, een groot gedeelte van de informatie die wordt besproken niet reproduceren (Hoofdstuk 3 en 4). In de literatuur zijn verschillende technieken bekend om 'recall' bij (oudere) patiënten te verbeteren. Het is belangrijk om selectief te zijn, prioriteiten te stellen en te zorgen dat informatie relevant is voor de situatie van de individuele patiënt. Dit onderzoek suggereert dat oudere patiënten beter in staat zijn om informatie te herkennen dan om informatie actief te reproduceren (Hoofdstuk 4). Juist de adviezen die actieve reproductie vereisen (bijvoorbeeld hoe bijwerkingen voorkomen kunnen worden) zijn belangrijk. Daarom moeten artsen en verpleegkundigen heel bewust prioriteiten stellen bij het geven van adviezen die om actieve reproductie vragen. Tevens is het raadzaam om alert te zijn op sensorische problemen, te voorkomen dat patiënten worden afgeleid door de omgeving, langzaam en duidelijk te praten en medisch taalgebruik (vakjargon) te vermijden. Daarnaast is het advies om informatie te structureren en te groeperen, 'bruggetjes' te maken tussen verschillende onderwerpen en de belangrijkste informatie samen te vatten en te herhalen. Ook is het van belang om verschillende manieren van informatie geven te combineren (bijvoorbeeld mondelinge voorlichting en een folder) en informatie te spreiden over verschillende momenten. Tot slot is de enige manier om echt te achterhalen wat de patiënt oppikt van het gesprek, de patiënt te vragen de relevante informatie in zijn eigen woorden samen te vatten.

Meer in het algemeen is het belangrijk dat de communicatie aansluit bij de individuele oudere patiënt met kanker en zijn of haar situatie, behoeften, wensen en emoties. We bespreken hier kort een aantal aanbevelingen voor verpleegkundige voorlichting-op-maat. Goede voorlichting vergt goede voorbereiding. Verpleegkundigen zouden dus voldoende tijd moeten krijgen om zich in te lezen en een agenda op te stellen voor het gesprek. Om optimale communicatie te garanderen, en daarmee de 'recall' van de oudere patiënt te verbeteren, is het belangrijk dat de verpleegkundige voor aanvang van het consult informatie heeft over de achtergronden van de patiënt (zowel medisch als sociaal) en zijn medisch dossier. Daarnaast is het essentieel dat de verpleegkundige beschikt over kuurinformatie van de specifieke behandeling

die de patiënt ondergaat, inclusief informatie over bijwerkingen die bij de betreffende kuur het meest voorkomen. Pas dan kunnen de juiste prioriteiten gesteld worden ten aanzien van adviezen over omgaan met bijwerkingen. Zeker met oudere patiënten is het belangrijk om informatie te kunnen geven in een rustige ruimte. Hoewel artsen altijd de beschikking hebben over een spreekkamer, is dit voor verpleegkundigen lang niet altijd vanzelfsprekend.

Tot slot

Dit proefschrift laat zien dat patiënten met kanker weinig kunnen reproduceren van de gesprekken met hun arts of verpleegkundige. Met name patiënten die ouder zijn en patiënten met een slechtere prognose hebben hier moeite mee. De patiënten in ons onderzoek werden geconfronteerd met veel en gedetailleerde informatie en het is de verwachting dat de hoeveelheid medische informatie die beschikbaar is voor patiënten in de toekomst alleen maar zal toenemen. Patiënten zullen nooit in staat zijn om alle informatie die op ze af komt te onthouden en zullen dus vaak een selectie maken. Het is de taak van artsen en verpleegkundigen om patiënten te helpen de informatie te onthouden die in hun specifieke situatie het meest essentieel is. Een belangrijk onderdeel hierbij is patiënten en hun families uit te nodigen tot het uiten van hun behoeften en emoties en vervolgens de informatie daar zoveel mogelijk op af te stemmen.

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Lieve Tjeerd, van Wageningen naar Amsterdam, van Amsterdam naar Sydney en van Sydney naar ... ? Jij bent er en dat is het aller belangrijkste. Here's to Bolle & Bolle!

Curriculum Vitae

Jesse Jansen (1978) studied psychology at the University of Amsterdam. As an undergraduate student, she did a research traineeship at the Medical Research Council, Cognition and Brain Sciences Unit in Cambridge, United Kingdom. In 2001, she graduated with a Masters thesis on cognitive functioning following chemotherapy. After obtaining her MA, she worked as a lab coordinator/researcher at the Department of Psychonomics, University of Amsterdam. In 2003 she started working at the NIVEL, since 2004 on her PhD-project that was funded by the Dutch Cancer Society. As a PhD candidate, she received travel grants from the Netherlands Organization for Scientific Research (NWO) and the René Vogels Foundation to conduct research at Sydney University. Since October 2008 she works at the Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), Sydney University, first at the Central Clinical School and since April 2009 at the School of Public Health. She currently works as an academic research psychologist and conducts experimental studies investigating health communication and decision-making.

“Nakata had nooit de illusie gehad dat zijn pogingen om met katten te communiceren perfect zouden verlopen. Als mensen en katten met elkaar communiceren zou het een wonder zijn als beide partijen hun bedoelingen helemaal foutloos aan elkaar duidelijk kunnen maken. In de eerste plaats waren er zo een paar probleempjes met Nakata's eigen conversatievaardigheden - of hij nu met mensen sprak of met katten. Weliswaar had hij vorige week zonder de minste moeite een gesprek met de heer Otsuka gevoerd, maar zo iets was eerder een uitzondering dan regel. In het algemeen was het niet eenvoudig om zelfs maar een simpele boodschap over te brengen. Op een slechte dag hadden man en kat meer weg van twee kennissen die elkaar op een winderige dag over een winderige rivier iets toeschreeuwen. En vandaag was het zo'n dag.”

Haruki Murakami

Kafka op het strand