

Université de Montréal

Health professionals' perception of distress in cancer patients and family members: Measuring accuracy and examining the role of empathic skills

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Thèse présentée à la Faculté des études supérieures
en vue de l'obtention du grade de Philosophiae Doctor (Ph.D.)
en psychologie recherche et intervention
option clinique

Juillet 2017

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Résumé

Le cancer est une expérience éprouvante pour les personnes touchées par cette maladie, qui doivent s'adapter à une variété de conséquences psychosociales. La gestion de la détresse psychologique chez les patients et chez leurs proches est un aspect fondamental des soins centrés sur la personne. De récentes avancées en recherche et en standards de pratique permettent un repérage plus précis de la détresse. L'administration systématique de tests de dépistage est devenue pratique courante. Cependant, plusieurs avenues intéressantes demeurent inexploitées. Le but principal de cette thèse était d'examiner les habiletés empathiques, notamment la prise de perspective, en tant que stratégies complémentaires pour améliorer le repérage de la détresse.

L'objectif de la première étude était d'examiner la capacité empathique des médecins à repérer la dépression chez les adultes atteints d'un cancer avancé. La recherche existante suggère que les professionnels ont de la difficulté à repérer la détresse de leurs patients avec précision. Nous avons examiné l'accord médecin-patient sur le niveau de dépression des patients, et ce, à l'aide de mesures plus fidèles et plus valides que celles typiquement rapportées dans la littérature. Afin de fournir des renseignements plus détaillés sur la performance des médecins, les analyses ont été réalisées au niveau des symptômes, ainsi qu'au niveau des scores globaux. Des analyses de régression ont servi à examiner la relation entre des variables d'habileté empathique et l'accord médecin-patient. Les résultats suggèrent que les médecins ont de la difficulté à repérer les symptômes dépressifs, particulièrement ceux de nature plus subtile. La capacité auto-rapportée des médecins à faire preuve de compassion, la qualité de leur relation avec le patient et leur sentiment d'auto-efficacité ont prédit un meilleur accord avec les patients sur un ou plusieurs symptôme(s) dépressif(s).

L'objectif de la deuxième étude était de comparer deux types de prise de perspective sur la capacité des soignants à repérer la détresse chez des parents d'enfants atteints d'un cancer. Une étude quasi-expérimentale a été conçue en intégrant des idées théoriques et méthodologies du domaine de la psychologie sociale. Divers professionnels en oncologie ont été aléatoirement répartis en deux groupes. Ils ont visionné une vidéo présentant des parents de patients pédiatriques. Les soignants du groupe *imagine-self* devaient s'imaginer comment ils se sentiraient et comment leur propre vie serait affectée s'ils se trouvaient dans les situations décrites par les parents. Les soignants du groupe *imagine-other* devaient s'imaginer comment les parents se sentaient et comment leur vie avait été affectée. En comparant les deux groupes, aucune différence significative n'a été obtenue pour l'accord soignant-parent sur les sentiments et les pensées des parents. Les soignants rapportant s'être mieux concentrés sur leurs propres sentiments, conformément à la perspective *imagine-self*, avaient tendance à obtenir un plus faible niveau d'accord. Le groupe *imagine-self* a rapporté significativement plus de détresse que le groupe *imagine-other*. Aucune association n'a été trouvée entre la détresse du soignant et l'accord soignant-parent.

Les habiletés empathiques pourraient améliorer le repérage de la détresse en oncologie. Ce domaine de recherche a le potentiel d'influencer la formation des professionnels, la gestion des ressources et possiblement la prévention de l'épuisement professionnel. La réalisation d'études expérimentales sera nécessaire à élaboration de recommandations fondées empiriquement.

Mots-clés: Repérage de la détresse, cancer, empathie, prise de perspective, soins centrés sur le patient, professionnels de la santé, parents

Abstract

Dealing with cancer and its treatment is an important life challenge for patients and family members, who must adapt to a variety of psychosocial consequences related to the illness. Managing psychological distress in persons affected by cancer is an important aspect of whole-patient and family-centred care. Recent advances in cancer care research and policy have allowed for more accurate detection of distress. Routine administration of screening tests is now common practice. However, many avenues are left unexploited. The principal aim of the present thesis was to examine empathic skills such as perspective taking as a complementary strategy for improving the detection of distress in adults affected by cancer.

The objective of the first study was to examine physicians' natural empathic ability to detect depression and general distress in adults with advanced cancer. Previous findings suggested that oncology professionals often struggle to accurately detect patient distress. We verified this phenomenon by employing more reliable and valid measures of patient-physician agreement than those most commonly reported in the literature. Analyses of agreement were conducted at both global and symptom levels in an effort to provide more detailed information on physicians' performance. In addition, regression analyses were performed to examine variables of empathic ability as possible correlates of patient-physician agreement on depressive symptoms. The results suggest that physicians have difficulty detecting depressive symptoms, particularly those that are more subtle in nature. Physicians' self-reported ability to provide compassionate care, quality of relationship with the patient, and self-efficacy in detecting patient distress, were all associated with higher patient-physician agreement on at least one depressive symptom.

The main objective of the second study was to compare two types of perspective taking on clinician ability to detect distress in parents of children with cancer. A quasi-experimental study was designed through the integration of basic theory and methodology from social psychology research. Oncology professionals were randomly assigned to one of two groups, and were then shown a video featuring parents of children with cancer. In the *imagine-self* group, they were instructed to imagine the feelings and life consequences which they would experience if they were in each parent's situation. In the *imagine-other* group, they were instructed to imagine the feelings and life consequences experienced by the parents. No significant group differences were found for parent-clinician agreement on parents' negative thoughts and feelings. However, clinicians who, in accordance with the imagine-self perspective, reported being more concentrated on their own feelings tended to show lower agreement. Clinicians who were instructed to adopt an imagine-self perspective reported significantly more distress than those instructed to adopt an imagine-other perspective. No association was found between clinician distress and parent-clinician agreement.

The findings of this thesis suggest that empathic skills could significantly contribute to accurate detection of distress in persons affected by cancer. This new line of research could have important implications for communication training, management of psychosocial resources, and possibly prevention professional burnout. More experimental research is needed before evidence-based guidelines can be elaborated.

Keywords: Detection of distress, cancer, empathy, perspective taking, patient-centred care, health care professionals, parents

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List of abbreviations

ESAS: Edmonton Symptom Assessment Scale

HADS: Hospital Anxiety and Depression Scale

PTSS: Post-traumatic stress symptoms

DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, 4th Edition

PTSD: Post-Traumatic Stress Disorder

DT: Distress Thermometer

DOR: Diagnostic odds ratio

ICC: Intra-class correlation coefficient

UHC: University Hospital Centre

NCCN: National Comprehensive Cancer Network

BDI-SF: Beck Depression Inventory – Short Form

JSPE: Jefferson Scale of Physician Empathy

CC: Compassionate Care subscale of the JSPE

PT: Perspective Taking subscale of the JSPE

ERS: Emotional Response Scale

IRI: Interpersonal Reactivity Index

SCID: Structured Clinical Interview for DSM Disorders

to Marguerite Durocher, Maria Adelaide de Almeida, and Denise Fugère

Acknowledgments

The present thesis project was made possible by the many individuals who have contributed to my work. I first thank Dr. Serge Sultan for believing in my ability to conduct innovative research in the field of psycho-oncology. Many hours of creative reflection lie at the foundation of this work. Thank you for assisting me in every step of the way.

I would also like to thank my research team. To the first cohort of Dr. Sultan's research students, thank you for embarking on this journey with me. You have been motivating, comforting, and inspiring. To the new cohort, thank you for keeping me determined when the process got long and tedious. Émélie Rondeau, you are the best research assistant and coordinator! Thank you for your help and support.

I would like to thank all of my co-authors: Sophie Lelorain, Anne Brédart, Sylvie Dolbeault, Angélique Bonnaud-Antignac, Florence Cousson-Gélie, Annie Janvier, France Dupuis, and Michel Duval. I would not have been able to conduct this interdisciplinary research without your collaboration. Many others have been involved in the recruitment of participants and data curation. My thanks go out to them as well.

I am grateful to all those who participated in my studies. Thank you to the individuals with advanced cancer and the parents of children with cancer for sharing your personal experiences. Learning about them has been a true privilege. Thank you to the health professionals for taking time out of your busy schedules. I hope this research will encourage you to care for yourselves as well as you do for your patients.

Thank you to the French National Cancer Institute, the Fonds de recherche du Québec – Société et culture (FRQSC), the CHU Sainte-Justine Foundation, the Larry and Cookie Rossy Foundation, and Industrial Alliance for their financial support.

Finally, I would like to thank my close friends and family for their support and positive energy. I would like to thank my father, Manuel Gouveia, for investing in my education and my mother, Jeannine Tardif, for teaching me to strive for my dreams. I would like to thank Annie Gouveia, my twin sister and best study buddy, for encouraging me to pursue my studies in psychology and for reading the entire thesis. Last but not least, I would like to thank Jean-Luc Martel, my partner in crime. You have helped me stay grounded and focused on my priorities. I love you and I look forward to pursuing life's journey with you by my side.

Chapter 1

General Introduction

Individuals with cancer and family members suffer greatly from the diverse psychological effects of the disease and its treatment. In recent years, detection of psychological distress has gained increased attention in cancer care research and clinical guidelines. National organizations, for example in Canada and the United States, now recommend regular administration of brief screening tools as a strategy for identifying patients and family members in need of further psychosocial assessment (Canadian Partnership against Cancer, 2012; National Comprehensive Cancer Network, 2013). Several studies support the feasibility and efficacy of this screening method (see Mitchell, 2013 for a review). However, much less research has examined the role of relational abilities in detection of distress. Findings indicate that oncology professionals often have difficulty accurately perceiving distress in persons affected by cancer (Chidambaram, Deshields, Potter, Olsen, & Chen, 2014; Mitchell, Hussain, Grainger, & Symonds, 2011; Patel et al., 2011; Werner, Stenner, & Schüz, 2011). Although standardized screening tests may serve to remediate part of this problem, clinicians tend to rely more heavily on their personal judgment (Mitchell, Kaar, Coggan, & Herdman, 2008; Pirl et al., 2007). Training aimed at improving social perception could potentially improve clinician accuracy. The present thesis considers the teaching of empathic skills as a complementary strategy to existing screening methods. It introduces a new line of research, based on interdisciplinary integration of theory and methodology. We hope this work will contribute to a more holistic approach to detection of distress in cancer care.

The following general introduction offers an overview of this project's rationale, theoretical background, and research objectives. Two research articles are then presented in separate chapters. The final chapter serves as a general discussion of the results and their implications.

Distress in Adults Affected by Cancer

Each person experiences cancer in his or her own way. While some are well equipped to manage difficult emotions and maintain an adequate level of functioning, others need professional assistance to overcome the often overwhelming challenges that accompany the illness. In practically all cases, patients and family members affected by cancer experience a certain amount of distress. Distress in the oncology setting has been defined as:

[...] a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (Holland et al., 2013, p.192)

Validating its importance in cancer care, the International Psycho-Oncology Society recently recognized distress as the sixth vital sign (Watson & Bultz, 2010). It is estimated that approximately 45.4% of cancer patients report clinical levels of distress on the Distress Thermometer (Mitchell, Hussain, et al., 2011), a common screening tool recommended by the National Comprehensive Cancer Network (Holland et al., 2013). A clinical level of distress does not necessarily imply the presence of a psychological disorder. Rather, it suggests a need for further psychosocial assessment and an increased likelihood of developing disorders such as

depression or anxiety. Cancer patients have been found to be at greater risk for developing mood disorders, compared to the general population. The prevalence rates for major depression and dysthymia amongst adult hematology-oncology patients are estimated at 14.9% and 2.7% (Mitchell, Chan, et al., 2011), compared to the normative 12-month prevalence rates of 7% and 0.5% (American Psychiatric Association, 2013), respectively. Post-treatment, they remain at risk for experiencing heightened depressive and/or anxious symptoms (Schumacher et al., 2013). Whether at a clinical or subclinical level, adults with cancer clearly experience a substantial amount of psychological distress in response to their illness and its related life impacts. Findings suggest that family members suffer as much as the patients themselves (e.g. Dumont et al., 2006; Edwards & Clarke, 2004; Grunfeld et al., 2004; Hodges, Humphris, & Macfarlane, 2005; Verdonck-de Leeuw et al., 2007). Accordingly, the present thesis examines detection of distress amongst adult patients, as well as family members. Two populations were selected for this research: adults with advanced cancer and parents of children with cancer. The following sections elaborate on the psychological distress associated with each of these groups.

Distress in Adults with Advanced Cancer

The specificity of distress associated with advanced cancer lies in the nature of patients' fears, which often concern the pain associated with death, the consequences death will have on close ones, and existential worries (Moorey & Greer, 2002). These fears are often accompanied by a depressive mood. Strömngren et al. (2001) conducted a study in Denmark with advanced cancer patients, and found that 47% and 67% of them reached clinically significant levels of depression on the Edmonton Symptom Assessment Scale (ESAS) and on the Hospital Anxiety and Depression Scale (HADS), respectively. Teunissen, de Graeff, Voest, and de Haes (2007) reported similar statistics. Most probably due to the complications involved in diagnosing

psychiatric disorders in persons with advanced cancer, the prevalence of depressive disorders in this population remains unclear. Indeed, many symptoms of depression such as fatigue or loss of energy, change in weight or appetite, insomnia, reduced concentration, and changes in psychomotor ability can be a direct consequence of the illness or its treatment (Mitchell, Lord, & Symonds, 2012). While some experts recommend relying on cognitive and affective symptoms to diagnose depression in persons with cancer, others argue that somatic symptoms are equally informative (McDaniel, Musselman, Porter, Reed, & Nemeroff, 1995; Trask, 2004). Either way, estimating prevalence rates for depression in this population is an important challenge. Diagnoses of adjustment disorders tend to be more common, with estimates ranging from 14% to 34.7% (Miovic & Block, 2007). Anxiety disorder diagnoses are generally less common than depressive disorder diagnoses (Miovic & Block, 2007; Spencer, Nilsson, Wright, Pirl, & Prigerson, 2010), although clinical levels of anxious mood are almost as common as that of depressive mood (Strömngren et al., 2001; Teunissen et al., 2007).

Distress in Parents of Children with Cancer

Anxious, depressive and post-traumatic stress symptoms (PTSS) are common amongst parents of children with cancer, especially in the first few months post-diagnosis (Fotiadou, Barlow, Powell, & Langton, 2008; Jantien Vrijmoet-Wiersma et al., 2008; Norberg & Boman, 2008). Uncertainty about treatment outcome and helplessness towards the child's suffering are important sources of parental distress (Rodriguez et al., 2011). Parental distress is most commonly conceptualized as post-traumatic stress. Results from self-report questionnaires indicate that 22% to 68% of parents of children with cancer experience clinically significant levels of PTSS (Ljungman, Hovén, Ljungman, Cernvall, & von Essen, 2015). For most parents, symptoms gradually decrease to normative levels after receiving the diagnosis. However, a

subset of parents remains with clinical levels of distress. A recent longitudinal study found that approximately 10% of mothers met full DSM-IV criteria for Post-Traumatic Stress Disorder (PTSD) five years post-treatment (Ljungman et al., 2015). The numbers climbed to 20% for partial PTSD (i.e. mothers who had one to three fewer symptoms than is required for a full DSM-IV diagnosis). Prevalence rates were lower for fathers of survivors (1.6% full PTSD; 7.8% partial PTSD). The normative 12-month prevalence rate for DSM-IV PTSD in America is 3.5% (American Psychiatric Association, 2013). Thus, pediatric cancer does seem to have lasting effects on parental distress. In fact, levels of PTSS and lifetime PTSD amongst parents of childhood cancer survivors have been found to be significantly higher than those observed amongst parents of healthy children (Jantien Vrijmoet-Wiersma et al., 2008).

Detecting Distress in Patients and Family Members

Detection of distress is crucial for preventing persistent psychological ill-being and impaired functioning in persons affected by cancer. According to standards of care, primary care and oncology professionals should be capable of detecting distress in cancer patients *and* their family members (Accreditation Canada, 2016; American College of Surgeons, 2012; Canadian Association of Psychosocial Oncology, 2010; Canadian Partnership against Cancer, 2012; National Comprehensive Cancer Network, 2013; Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Physicians, nurses and other clinicians are expected to refer individuals with elevated and/or chronic levels of distress to psychosocial services for further assessment.

In addition to fostering psychosocial well-being, recognizing patient and family distress may lead to improved medical care. Distress is often a sign of unmet needs. Lack of information, untreated pain, and poor understanding of medical information are just a few examples of treatment-related factors that can contribute to psychological distress. Acknowledgment of

patient/parent negative emotions and concerns allows for better identification of such problems. It is an essential part of autonomy support, which is associated with greater treatment adherence and habit change (Julien, Senécal, & Guay, 2009; Kennedy, Goggin, & Nollen, 2004; Laurin & Lavoie, 2011; Williams et al., 2006). In contrast, unacknowledged or untreated distress may lead to poorer adherence. Colleoni et al. (2000) found that breast cancer patients were much less likely to accept adjuvant chemotherapy when depressed. Similarly, Embry (2003) reported that anxiety in both parents and pediatric patients predicted lower adherence rates. To the extent that it encourages empathic communication and psychosocial intervention, detection of distress can potentially enhance both medical and psychosocial aspects of cancer care.

Despite the importance of detecting distress in persons affected by cancer, research suggests that clinicians, namely nurses and physicians, often struggle to accurately identify psychological symptoms and patterns in adult patients. Indeed, patient-clinician agreement on self-report and proxy questionnaires is generally poor (e.g. Mitchell et al., 2012; Werner et al., 2011). One study's findings suggested that clinicians' perception of distress levels amongst parents of children with cancer is equally inaccurate (Patel et al., 2011).

In analyses of patient-clinician agreement, distress scores are most commonly dichotomized into presence versus absence of distress. This is usually achieved using the questionnaire's validated cut-off point. Kappa values serving as indices of agreement have ranged from .04 to .44 (Chidambaram et al., 2014; Fukui, Ogawa, Ohtsuka, & Fukui, 2009; Keller et al., 2004; Lampic, von Essen, Peterson, Larsson, & Sjoden, 1996; McDonald et al., 1999; Mitchell, Hussain, et al., 2011; Passik et al., 1998; Söllner et al., 2001; Trask et al., 2002; Werner et al., 2011), indicating poor patient-clinician agreement (Landis & Koch, 1977). Many studies also report sensitivity (number of cases detected by clinicians/ total number of cases)

and specificity (number of non-cases detected by clinicians/ total number of non-cases) as indices of agreement. Sensitivity on questionnaires measuring general distress has ranged from 28.7% to 86%, while specificity has ranged from 48% to 97% (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Keller et al., 2004; Mitchell, Hussain, et al., 2011; Söllner et al., 2001; Trask et al., 2002). This implies that clinicians are generally better at recognizing the absence of distress than they are at recognizing its presence. Recognition of depressive symptoms has been found to be particularly difficult, with sensitivity values ranging from 12.2% to 30.4% (Okuyama et al., 2011; Passik et al., 1998; Werner et al., 2011). Taken together, these findings suggest poor clinician accuracy on psychological distress.

Professionals of all types seem to have difficulty recognizing symptoms, although nurses tend to show higher sensitivity than physicians (Fallowfield et al., 2001; Fukui et al., 2009; Keller et al., 2004; Mitchell, Hussain, et al., 2011; Okuyama et al., 2011; Söllner et al., 2001; Trask et al., 2002; Werner et al., 2011). Clinician ethnicity, on the other hand, has not been found to be associated with differences in detection accuracy (Keller et al., 2004; Mitchell, Hussain, et al., 2011; Okuyama et al., 2011; Söllner et al., 2001; Werner et al., 2011).

National organizations (Canadian Partnership against Cancer, 2012; National Comprehensive Cancer Network, 2013) have addressed the problem by recommending regular administration of brief screening tests such as the Distress Thermometer (DT; Roth et al., 1998) and the Edmonton Symptom Assessment System (ESAS; Watanabe et al., 2011). These instruments typically include a problem checklist and visual analogue scales assessing levels of general distress and/or specific symptoms. Screening tests are certainly part of the solution. However, there are a few limits to solely relying on these tools. Indeed, brief tests like the DT have limited validity (Mitchell et al., 2007), are especially sensitive to change (Leclair, Carret,

Samson, & Sultan, 2016), and cannot be used in all contexts. Due to time constraints, screening of distress is typically conducted in the waiting room. However, patients and family members occasionally show important signs of distress at other times during their hospital visit. In consultation, for example, patients and family members may show symptoms of distress that would normally go undetected by screening tests. Empathic skills serve as a useful tool, as they allow clinicians to notice and investigate spontaneous expressions of distress. In fact, studies have found that physicians rely mostly on their own judgment to screen for distress (Mitchell et al., 2008; Pirl et al., 2007). Advocating for the use of empathic skills in combination with screening tests would most likely allow for greater flexibility and more accurate detection of distress.

Empathy as a Skill for Detecting Distress

As stated in the previous section, empathic skills could possibly contribute to accurate detection of distress by clinicians in oncology. In clinical and health research, the ability to accurately detect distress experienced by patients and family members is often referred to as *clinical empathy*. Coulehan et al. (2001) define clinical empathy as “the ability to *understand* the [...] [person’s] situation, perspective, and feelings and to *communicate* that understanding to the [...] [person].” Theoretically then, effective training programmes in clinical empathy should compensate for at least some of screening tests’ shortcomings. There is preliminary evidence of this; a correlational study found that physicians who scored highly on empathy also showed higher agreement with patients on psychological symptoms (Yagil, Biron, Pat, Mizrahi-Reuveni, & Zoller, 2015). However, theories and correlational studies provide insufficient support for the implementation of effective training programmes. For this, it is necessary to identify and test specific and teachable skills. Existing studies tend to focus on the

“communication” aspect of empathy. In the empathy module of the Memorial Sloan Communication Skills Training programme for oncology nurses, for instance, empathy is broken down into twelve communication skills, including acknowledging feelings, encouraging expression of emotions, asking open questions, clarifying, normalizing, and making partnership statements (Pehrson et al., 2016). It is hypothesized that empathic communication leads to better understanding of patients by encouraging self-disclosure (Neumann et al., 2009). Two studies found that clinicians who received extensive training in empathic communication showed more accurate detection of distress (Fukui et al., 2009; Merckaert et al., 2008). This suggests that communication centred on acknowledgment of patient feelings and encouragement of patient emotional expression by oncology clinicians may lead to better detection of distress. However, fewer studies have examined the “understanding” aspect of empathy as a teachable skill. Hojat et al. (2002) refer to it as the “cognitive domain of empathy [which] involves the ability to understand another person’s inner experiences and feelings and a capability to view the outside world from the other person’s perspective.” Although the cognitive task of understanding patient distress is closely related to empathic communication, it remains largely ignored. Namely, *perspective taking* is a skill rarely taught to oncology professionals in empathy or communication training programmes. To our knowledge, the relationship between perspective taking and detection of patient distress by clinicians has yet to be studied. The following section describes this skill as a crucial cognitive step in the empathic process of understanding patient and family distress.

Perspective Taking: A Simple and Teachable Skill

Davis (2004) defines perspective taking as “the attempts by one individual to understand another by imagining the other’s perspective.” In psycho-oncology research, perspective taking

is generally construed as one unitary skill associated with greater patient satisfaction (Blatt, LeLacheur, Galinsky, Simmens, & Greenberg, 2010). This approach differs from that of basic research in social psychology, which distinguishes between different types of perspective taking. The most prominent model was proposed by Batson (2009). His theory stipulates that there exist two types of perspective taking: imagine-self and imagine-other. *Imagine-self* perspective taking is defined as the cognitive act of imagining how one would feel in another person's difficult situation, and how that would affect his/her life. Alternately, *imagine-other* perspective taking refers to imagining how the other feels and how the situation has affected his/her life (Batson, 2009). Experimental studies have found that participants instructed to adopt an imagine-self perspective experience significantly more self-oriented distress (e.g. feeling troubled, low-spirited, alarmed) and engage in relatively more egotistic behaviour, compared to those instructed to take an imagine-other perspective (Batson, Early, & Salvarani, 1997; Batson et al., 2003; Lamm, Batson, & Decety, 2007). Accordingly, imagine-other perspective taking is associated with proportionally more empathic concern (e.g. feeling compassionate, touched, concerned) and altruistic behaviour (Batson et al., 1997; Batson et al., 2003; Lamm et al., 2007). In Batson et al. (2003)'s experiments, for instance, participants were instructed to assign a set of tasks to themselves and another fictitious participant. The imagine-other group showed significantly higher fairness in task assignment than did the imagine-self group. Hence, it is thought that individuals with an imagine-self perspective engage in egoistic behaviour to decrease personal distress (Batson, 2009).

Batson's conceptualization of perspective taking types, along with their differential effects on emotion and behaviour, highly resembles the common distinction between empathy and sympathy, as defined by Hojat, Spandorfer, Louis, and Gonnella (2011). On one hand,

clinical empathy is defined as understanding the patient's personal experience. This is the implicit goal of the imagine-other perspective. On the other hand, researchers in the medical field define sympathy as the sharing of patients' emotions (Hojat et al., 2002; Hojat et al., 2011; Nightingale, Yarnold, & Greenberg, 1991). This resembles the imagine-self perspective. It follows that the imagine-other perspective could lead to relatively better understanding of patient distress (empathy), while the imagine-self could lead to relatively higher clinician distress (sympathy). This idea is consistent with the associations found between the imagine-self perspective and observer distress. However, the effect of perspective type on the observer's accuracy remains poorly investigated. Thus, an important aim of the present thesis was to compare the imagine-other and imagine-self perspectives as clinical strategies for detecting distress. Although empathy and sympathy are related (Hojat et al., 2001; Hojat et al., 2011), excessive sympathy is thought to interfere with clinician objectivity (Hojat et al., 2002; Hojat et al., 2011; Nightingale et al., 1991). Similarly, a strong imagine-self perspective could possibly hinder clinician accuracy on patient distress.

To date, only one research team has investigated the differential effects of the two types of perspective taking on detection of patient distress. These quasi-experimental studies showed that informal caregivers instructed to adopt an imagine-other perspective were significantly more accurate on cancer patients' distress symptoms, compared to those instructed to adopt an imagine-self perspective (Lobchuk, Degner, Chateau, & Hewitt, 2006; Lobchuk, McClement, Daeninck, Shay, & Elands, 2007; Lobchuk & Vorauer, 2003). This finding supports the aforementioned idea, suggesting that the imagine-other perspective might yield greater accuracy than the imagine-self perspective. Nonetheless, these studies suffer from a few limitations. First, patient-caregiver agreement was measured as the absolute difference between patient and

caregiver ratings of distress symptoms. Such a method risks confounding relatively insignificant differences with important ones, since it fails to interpret the position of the original scores on the rating scale. It also allows for very little variation in difference scores, which in this case ranged from 0 to 3. Secondly, one could argue that part of the perspective taking instructions was inconsistent with Batson et al. (1997)'s original protocol. The imagine-other prompt instructed participants to "put themselves in the patient's shoes" (Lobchuk et al., 2007), a phrase which could be thought to easily induce an imagine-self perspective. Thus, Lobchuk et al.'s findings should be interpreted with caution.

Other lines of socio-cognitive research provide more indirect support to the hypothesized link between perspective type and accurate detection of distress. To begin, findings in neuro-imaging suggest that the imagine-self perspective could blur the boundary between mental representations of the self and the other. Indeed, the two perspective types have shown differences in brain activation, namely in areas of the right parietal lobe associated with self-other differentiation (Jackson, Brunet, Meltzoff, & Decety, 2006; Lamm et al., 2007; Ruby & Decety, 2001, 2004). These findings corroborate those of research on thought content. In one of their experiments, Wilkes, Milgrom, and Hoffman (2002) found that participants adopting an imagine-other perspective reported more other-related cognitions, compared to participants adopting an imagine-self perspective. In contrast, the latter reported more self-related thoughts. A more recent study found that the imagine-self perspective was associated with greater perceived self-other overlap, defined as "conscious perceptions of closeness and a more implicit form of overlap in describing the self and other" (Myers, Laurent, & Hodges, 2014). Such findings indicate that the imagine-other perspective could lead to better self-other differentiation. Theoretically, this should reduce self-related bias and increase accurate

perception of the other's distress. Moreover, research in emotion recognition suggests that clinician distress per se could bias perception of patient distress (Gery, Miljkovitch, Berthoz, & Soussignan, 2009; Lampic et al., 1996; Schmid & Schmid Mast, 2010). Here again, the imagine-other perspective would be at an advantage, since the imagine-self perspective is associated with higher distress. Taken together, findings on the cognitive and affective processes involved in perspective taking point to imagine-other perspective taking as the best perspective taking strategy for accurate detection of distress.

Gaps and Limitations in the Literature

The literature on clinical empathy and detection of distress contains important gaps and limitations. To begin, there remains a dearth of research examining the possible impact of empathic skills, especially perspective taking, on detection of distress in persons affected by cancer. Many more intervention studies have yet to be conducted before evidence-based recommendations for empathy training can be elaborated. Although recent research suggests that empathic skills such as imagine-other perspective taking could improve recognition of distress in persons affected by cancer (Lobchuk et al., 2007; Merckaert et al., 2008; Yagil et al., 2015), this hypothesized causal link has yet to be tested experimentally in the context of patient-clinician or parent-clinician dyads. An important barrier to testing the efficacy of interventions aimed at improving detection of distress is the lack of measurement methods which allow for examination of clinician accuracy as a continuous variable. As previously discussed, measuring patient-clinician agreement as the absolute difference between patient and clinician scores on distress questionnaires risks undermining important information on the magnitude of individual disagreements. The present thesis addresses this limitation by integrating in its methods a

theoretically grounded and psychometrically validated inter-subject measure of accuracy proposed by Marangoni, Garcia, Ickes, and Teng (1995).

To continue, studies on detection of distress often lack adequate global indices of patient-clinician agreement. For instance, the Kappa statistic, sensitivity, and specificity are highly influenced by prevalence rates of patient distress (Lampic & Sjöden, 2000; Peat & Barton, 2005). Pearson correlations are equally inappropriate, since they fail to account for absolute distance between patient and clinician scores. The present research employs better alternatives that allow for more reliable assessment of global patient-clinician agreement, including the diagnostic odds ratio (DOR) and the intra-class correlation coefficient (ICC; Glas, Lijmer, Prins, Bonsel, & Bossuyt, 2003; Peat & Barton, 2005).

Finally, an important limit to existing research on clinician ability to detect distress is the lack of studies aimed at identifying the exact symptoms which clinicians have difficulty recognizing. Most often than not, studies have examined patient-clinician agreement on general distress, anxiety and depression. However, the identification of specific symptoms that are particularly difficult to detect would provide valuable teaching material for clinical training. To address this gap in the literature, we performed many of our analyses at a symptom level.

Objectives

The first objective of the present thesis was to study clinician ability to detect distress in persons affected by cancer using improved methods. This was accomplished by a) implementing more reliable and valid measures of patient-clinician agreement than those most commonly reported in the literature, and b) conducting symptom-level analyses of agreement, in addition to examining agreement on global scores of distress.

The second objective was to identify empathic skills that would allow for better clinician accuracy. This was accomplished by a) examining self-reported variables of empathic ability as potential correlates of clinician accuracy on depressive symptoms in patients with advanced cancer, and b) comparing two types of perspective taking (imagine-self and imagine-other) on clinician ability to identify negative thoughts and feelings in parents of children with cancer. Also of interest were the consequences of these strategies on clinician distress.

Thesis Structure

The second chapter of the present thesis presents an article entitled “Oncologists’ perception of depressive symptoms in patients with advanced cancer: Accuracy and relational correlates,” published in BMC Psychology. This study primarily addresses the first of the two objectives described above. It reports on physician ability to detect key depressive symptoms in adults with advanced cancer via statistical indices of global patient-physician agreement. The study also serves as a preliminary step for the second objective, examining the relationship between empathy variables and patient-physician agreement on patient depressive symptoms and on general distress in a set of correlational analyses.

The third chapter presents an article entitled “Comparing two types of two types of perspective taking as strategies for detecting distress amongst parents of children with cancer: A randomized trial,” published in PLOS ONE. It primarily addresses the second objective by examining the differential effects of perspective taking on clinician ability to detect negative thoughts and feelings experienced by parents of children with cancer. This study serves as a subsequent step to the correlational analyses presented in the first article, focusing on perspective taking as a specific empathic skill, and employing more rigorous measures and

research design. It also presents valuable findings concerning the impact of perspective type on clinician distress.

The fourth and final chapter presents a general discussion revisiting the main objectives and conclusions of the present thesis. In addition, this section introduces new reflections on the challenges involved in this work as a whole, as well as its theoretical and practical implications.

Co-Authors' Contributions

For the first article presented in chapter 2, the author of the thesis, Lucie Gouveia, analyzed the data and wrote the manuscript. The data was initially collected by Dr. Sophie Lelorain, along with her colleagues, Dr. Anne Brédart, Dr. Sylvie Dolbeault, Pr. Angélique Bonnaud-Antignac, and Dr. Florence Cousson-Gélie. The whole project was supervised by Dr. Serge Sultan, who also reviewed the manuscript. All co-authors contributed their input prior to publication. For the second article presented in chapter 3, the author of the thesis elaborated the study, obtained consent from the Sainte-Justine UHC ethics committee, recruited the participants, collected the data, performed the statistical analyses and wrote the manuscript. The whole research process was conducted under the supervision of Dr. Serge Sultan. Dr. Annie Janvier contributed to the planning of the stimulus video and helped Dr. Sultan review the final manuscript. Dr. Dupuis contributed to recruitment of the nursing students, while Dr. Michel Duval contributed to recruitment of oncology professionals at the Charles-Bruneau Cancer Centre. All co-authors contributed their input prior to publication.

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doi:10.1016/j.pec.2015.07.008

Chapter 2

First Article

Oncologists' perception of depressive symptoms in patients with advanced cancer: Accuracy and relational correlates

Gouveia, L., Lelorain, S., Brédart, A., Dolbeault, S., Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2015). Oncologists' perception of depressive symptoms in patients with advanced cancer: Accuracy and relational correlates. *BMC psychology*, 3(1), 6.

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Oncologists' perception of depressive symptoms in patients with advanced cancer: Accuracy and relational correlates

Running head: Oncologists' perception of depression in patients with advanced cancer

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Abstract

Introduction: Health care providers often inaccurately perceive depression in cancer patients. The principal aim of this study was to examine patient-oncologist agreement on specific depressive symptoms, and to identify potential correlates of accurate detection. Methods: 201 adult advanced cancer patients (recruited across four French oncology units) and their oncologists (N=28) reported depressive symptoms with eight core symptoms from the BDI-SF. Various indices of agreement, as well as logistic regression analyses were employed to analyze data. Results: For individual symptoms, medians for sensitivity and specificity were 33% and 71%, respectively. Sensitivity was lowest for suicidal ideation, self-dislike, guilt, and sense of failure, while specificity was lowest for negative body image, pessimism, and sadness. Indices independent of base rate indicated poor general agreement (median DOR = 1.80; median ICC = .30). This was especially true for covert symptoms such as sense of failure, self-dislike and guilt. Depression was detected with a sensitivity of 52% and a specificity of 69%. Distress was detected with a sensitivity of 64% and a specificity of 65%. Logistic regressions identified compassionate care, quality of relationship, and oncologist self-efficacy as correlates of patient-physician agreement, mainly on the less recognizable symptoms. Conclusions: The results suggest that oncologists have difficulty accurately detecting depressive symptoms. Low levels of accuracy are problematic, considering that oncologists act as an important liaison to psychosocial services. This underlines the importance of using validated screening tests. Simple training focused on psychoeducation and empathic skills would also allow for better detection of key depressive symptoms that are difficult to perceive.

Introduction

Depression is a common emotional experience in people with advanced cancer. A review of the literature (Mitchell et al. 2011) suggests that many patients in palliative care suffer from adjustment disorders (~15.4%), minor depressive disorders (~9.6%), or major depression (~16.5%). Indeed, patients with brain metastases have been found to report more emotional symptoms than physical complaints (Cordes et al. 2014). Strömngren et al. (2001) found that, amongst 102 patients with advanced cancer, more than half reported significant levels of depression. However, less than a third of these cases were reported in medical records. Similar findings have repeatedly been reported in the general cancer population, suggesting that physicians and other health care professionals (clinicians) may inaccurately perceive patient distress, particularly depression (Lampic and Sjöden 2000; Werner et al. 2012; Keller et al. 2004; Trask et al. 2002). This is problematic considering that clinicians serve as the first line to psychosocial services. In addition to disrupting resource allocation, failing to understand the patient's personal experience can hinder the collaborative process on which important medical decisions rest. Few studies have examined this issue amongst individuals with late-stage cancer. The aim of this study was to better understand detection of depression in advanced cancer patients by measuring patient-oncologist agreement on specific depressive symptoms and by examining the relationship between variables of empathic ability and accurate detection.

Physician Accuracy on Patient Depression

Depression is defined by the World Health Organisation "as a common mental disorder, characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness and poor concentration" (World Health Organisation: Regional Office for Europe 2015). In the context of cancer care, it can be

understood as a type of distress, defined by the National Comprehensive Cancer Network (NCCN) as an “unpleasant emotional experience” which varies in magnitude and may interfere with coping abilities (Holland et al. 2013). Although depression may be referred to as a psychiatric diagnosis, the term is also used to describe subclinical levels of the disorder, as in the present research. The definition also varies according to the method of measurement. Over the past few decades, it has consistently been reported that clinicians often fail to detect depression in cancer patients (e.g. Lampic and Sjöden 2000; Okuyama et al. 2011; Werner et al. 2012). Although diverse statistical indices have been employed to assess clinician accuracy on patient depression, findings generally converge.

Patient ratings of their own depression are typically used as the reference point against which clinician ratings are compared. While some studies use standardized tools for patients and clinicians, others only do so for patients. Most commonly reported is sensitivity (number of cases detected by clinicians/ total number of cases) and specificity (number of non-cases detected by clinicians/ total number of non-cases). Low sensitivity values of 12.2% to 30.4% suggest that physicians have difficulty detecting depression when it is present. Specificity (74% to 97%) is generally higher, which may reflect a tendency to prematurely rule out depression (Passik et al. 1998; Werner et al. 2012; Okuyama et al. 2011).

Kappa statistics evaluating agreement between patient and physician ratings of patient distress range from .04 to .17 (Keller et al. 2004; Passik et al. 1998; Werner et al. 2012; Fukui et al. 2009; Söllner et al. 2001; Chidambaram et al. 2014), indicating poor accuracy (Landis and Koch 1977). Despite rare contradicting reports, most recent studies support the idea that oncologists struggle to discriminate between cases and non-cases of depression.

Although several studies deal with recognition of depression in cancer patients, almost none have detailed their results at the symptom level. This represents a major gap in the literature considering that detection of depression is contingent on the recognition of specific signs. To our knowledge, only one research team has taken a symptomatic approach. Passik et al. (1998) reported findings suggesting that physicians' perception of symptoms associated with visible signs might be more accurate than that of other less obvious ones. No additional studies have further pursued this hypothesis.

Another issue is the use of inappropriate indices of accuracy (Passik et al. 1998; Trask et al. 2002; Werner et al. 2012) where other indices are recommended (Peat and Barton 2005; Glas et al. 2003). A simple product-moment correlation, for example, does not reflect the absolute agreement between two ratings, but rather their similarity in ranking. The intraclass correlation coefficient (ICC) is preferable, as it accounts for the distance between physician and patient scores (Peat and Barton 2005). For the analysis of dichotomous variables, an index of agreement which is much less dependent on prevalence than the kappa is the diagnostic odds ratio¹ (DOR), which represents the odds of caseness in 'test positives' (i.e. patients rated as distressed by oncologists) relative to the odds of caseness in 'test negatives' (i.e. patients rated as not distressed by oncologists; Glas et al. 2003).

Key Symptoms of Depression in Adult Oncology

There has been much discussion around distinctive symptoms of depression in the medically ill (Trask 2004). Various screening instruments exclude somatic symptoms, which typically overlap with the side effects of physical illness. In accordance with this, research suggests that affective and cognitive symptoms are optimal for identifying depression in this population (Sultan et al. 2010), as they lower the rate of false negatives. Studies in cancer care

support this idea (Reuter et al. 2004; Warmenhoven et al. 2012). Key symptoms may differ according to cancer stage, due to changes in somatic symptoms and patient status (Mitchell et al. 2012). This has yet to be verified, as there is little research on detection of depression amongst patients with advanced cancer, possibly due to recruitment and attrition difficulties.

Potential Correlates of Accurate Detection

Based on preliminary research, many relational factors seem to influence oncologists' ability to accurately detect depressive symptoms in their patients. For example, a number of studies indicate that physicians' empathic attitude and skills have an important impact on how accurately they perceive distress in cancer patients, as well as the extent to which patients feel understood (Razavi et al. 2003; Merckaert et al. 2008; Fukui et al. 2009). According to Neumann et al. (2009)'s model, an empathic style of communication increases the accuracy of caregivers' perceptions and diagnoses by encouraging patient disclosure. More generally, it is thought that the quality of the patient-physician relationship allows for better detection of distress (Newell et al. 1998; Ryan et al. 2005).

Another variable of empathic ability which may enhance perception of patient depression is oncologists' self-efficacy in detecting distress. In fact, confidence in personal skills appears to be one of the main barriers to successful screening (Mitchell et al. 2008). However, this idea deserves to be nuanced, as the construct of self-efficacy is easily confounded with overconfidence, a characteristic which may harm rather than enhance performance (Moores and Chang 2009).

Study Objectives

Our first objective was to estimate oncologists' ability to accurately detect individual depressive symptoms amongst advanced cancer patients, in addition to depression and

psychological distress, and to compare the results across symptoms. It was hypothesized that patient-oncologist agreement would be lower for less obvious symptoms (sense of failure, guilt, self-dislike, suicidal ideation), compared to more recognizable ones (sadness, pessimism, negative body image). Unlike the former, the latter are associated with specific cues, such as crying/droopy facial expression (sadness), reactions to negative prognoses (pessimism) and hair loss (negative body image). We also wanted to identify key symptoms which contribute to accurate detection of depression and distress. The second main objective was to examine the relationship between variables of empathy (i.e. physician-reported perspective taking, compassionate care, self-efficacy in detecting distress, and quality of relationship with patients) and oncologist accuracy on each symptom.

Method

Procedure

A cross-sectional design involving patient-physician dyads was elaborated. Oncologists at the 'Institut Curie' (Paris and Saint-Cloud), the 'Institut de Cancérologie de l'Ouest' (Nantes), the 'Hôpital Nord Laennec' (Nantes), and the 'Polyclinique Bordeaux Nord Aquitaine' (Bordeaux) were invited to participate. Those interested completed questionnaires examining empathy-related characteristics. Each physician was asked to choose ten of their own patients meeting a set of selection criteria (see below). In consultation, they introduced the study to these patients, and handed them a consent form with depression and distress questionnaires. Patients who agreed to participate had one week to complete the documents and mail them back to the coordinating centre in a pre-paid envelope. The physicians completed an analogous set of questionnaires in a perspective taking task (Sultan et al. 2011), in which they provided the answers which they thought their patient had given. This paradigm allowed the assessment of

patient-physician agreement. The protocol was approved by the institutional review board of the Institut Curie (DR-2011-318) and by the French National Advisory Committee for the Processing of Information in Health Research (11.202).

Participants

Oncologists.

Sixty-four oncologists were contacted. Of these, 14 refused to participate, 11 had ineligible patients, and 11 accepted but did not follow through for reasons related to time and/or motivation. Twenty-eight oncologists (10 male) participated in the study. Differences between these participants and those who dropped out are unknown. The age of participating oncologists ranged from 31 to 64 years (Table 2.1).

Patients.

The sample of patients for the present study consisted of 201 advanced cancer patients (146 female). To participate, patients needed to meet the following criteria: age 18+ years, metastatic cancer from and beyond the 4th line of chemotherapy for primary breast cancer, or from and beyond the 2nd line of chemotherapy for any other type of primary cancer. Patients had to have already consulted the physician at least three times prior to their inclusion, so that they had a minimum knowledge of each other (Lelorain et al. 2014). Exclusion criteria were confirmed psychiatric pathology and hematological cancers. The age of patients ranged from 27 to 89 years old. Diagnoses included breast cancer (45.3%), colorectal cancer (20.9%), lung cancer (14.9%), and others (18.9%; Table 2.1).

Measures

Depression and depressive symptoms.

A short form of the Beck Depression Inventory (BDI-SF; see Appendix A for all questionnaires) was used to measure Depression and depressive symptoms (Collet and Cottraux 1986). Each item refers to one cognitive or affective symptom (Self-Dislike, sense of Failure, Guilt, Negative Body Image, Pessimism, Suicidal Ideation, Sadness, and Dissatisfaction with life), and was selected for medical settings (Beck and Beck 1972; Sultan et al. 2010). For each item, the responder chooses one of four statements of varying intensity (0-3), according to his/her present state. A cutoff of 3 yields the best trade-off between sensitivity and specificity when screening for depression in patients with chronic illnesses (Sultan et al. 2010). The internal consistency for this sample was very good ($\alpha = .81$). Convergent and predictive validity have also been supported (Furlanetto et al. 2005). In a population of women with metastatic breast cancer, the BDI-SF performed better than the Hospital Anxiety and Depression Scale in screening for DSM-IV depressive disorders (Love et al. 2004). It has been shown to recognize 88% of clinical cases amongst diabetes patients (Sultan et al. 2010). In this study, individual items served as measures of symptoms. A cutoff of 1 was used, discriminating between presence and absence of any given symptom.

Distress.

Distress was assessed via the Distress Thermometer (DT; Dolbeault et al. 2008), originally developed by Roth et al. (1998). This visual analogue scale ranges from 'no distress' to 'extreme distress.' The DT is recommended by the NCCN (Holland et al. 2013). A cutoff score of 4/10 is recommended, and has been identified as optimal for research purposes in a sample of cancer survivors (Boyes et al. 2013). As a screening test, the DT rarely misses clinical

cases of distress, though it does not reliably exclude subclinical ones (e.g. Mitchell 2007). A more thorough evaluation is needed when looking to identify purely clinical cases.

Potential correlates of patient-physician agreement.

Four variables relating to empathic ability were assessed. Physicians completed the Jefferson Scale of Physician Empathy (JSPE; Hojat et al. 2002). Confirmatory analyses of the French version have failed to support the existence of an overarching global factor (Zenasni et al. 2012). However, support was found for two factors within the questionnaire: Compassionate Care (CC) and Perspective Taking (PT). While the latter measures a cognitive aspect of empathy, the former concerns emotional processes (Hojat et al. 2002). The PT and CC scores consist of ten and eight items, respectively. In the present database, Cronbach's alphas were .57 (CC), .64 (PT), and .74 (total). Despite support for the questionnaire's construct validity (Glaser et al. 2007), it is undermined by low internal consistency.

Physicians also rated their sense of self-efficacy in detecting patient distress on a self-developed Likert scale: "In general, I feel competent to detect my patients' emotional distress and needs (1 = strongly disagree; 7 = strongly agree)." Post-consultation, they rated the quality of the patient-physician relationship using a similar scale: "What is the quality of your relationship with this patient? (1 = very difficult relationship; 7 = very easy relationship)."

Statistical Analysis

The DOR and the ICC² were used to calculate agreement between patients' and physicians' scores on patient Depression, depressive symptoms, and Distress. Patient ratings on the BDI-SF and the DT were used as reference points against which physician ratings were compared. To allow for inter-study comparisons, we also calculated other indices typically seen in the literature, such as the kappa statistic.

To identify which symptoms best contributed to patient-physician agreement on Depression and Distress, two stepwise logistic regressions were performed. Agreement (versus disagreement) on Depression (1st model) or Distress (2nd) was entered as the dependent variable. Eight predictor variables (patient-physician agreement/disagreement on each symptom) were then entered in both models, using the forward Likelihood Ratio method. Agreement versus disagreement was determined for each dyad according to the established cutoffs (i.e. 3 for Depression, 1 for depressive symptoms and 4 for Distress).

Next, a hierarchical logistic regression model was constructed, entering control variables in the first block and then adding the four predictor variables in a second block. This model was run to predict agreement on each of the eight symptoms, as well as Depression and Distress. Due to lack of research, the confounding factors are unclear. Control variables were thus identified from the study's large dataset. Correlation analyses were performed on sociodemographic and clinical variables, to determine their relationship with patient-physician agreement on Depression, individual depressive symptoms, and Distress. Significant correlations were retained as control variables (Cohen 1988).

Analyses were performed through IBM SPSS Statistics 20 and an alpha level of .05 was set for statistical significance.

Results

Preliminary Analyses

The mean Depression score was 3.94 (SD = 3.33), with a 51.5% rate of significant depression. Pessimism (51.8%) and Sadness (42.6%) were the most prevalent depressive symptoms. Guilt (14.0%) and Suicidal Ideation (17.0%) were the rarest. The mean Distress score was 1.80 (SD = 1.60), with a 25.9% rate of significant distress.

Mean level comparisons indicate moderate differences between physician and patient scores on Distress ($d = -.76$; 49.3% overestimation). Small differences were found for Suicidal Ideation ($d = .33$; 13.4% underestimation) and Negative Body Image ($d = -.30$; 39.8% overestimation). Weak differences were found for Sadness ($d = -.22$; 32.8% overestimation) and Pessimism ($d = -.20$; 36.3% overestimation). No significant differences were found on the remaining symptoms and Depression scores (Table 2.2).

Patient-Physician Agreement

Sensitivity was only slightly higher for Depression (68.9%) than for Distress (64.3%; Table 2.3). Specificity was higher for Distress (64.7%) than for Depression (52.0%). Regarding symptoms, sensitivity was highest for Pessimism (73.5%), Negative Body Image (68.4%), and Dissatisfaction (49.2%). Specificity was highest for Suicidal Ideation (94.6%), Self-Dislike (85.1%), and Guilt (84.9%).

Percent agreement and the kappa coefficient were not coherent. All kappa values indicated only slight agreement, except that of Depression which indicated fair patient-physician agreement ($\kappa = .21$).

The DOR obtained for Depression was small (2.41; Rosenthal 1996), although near moderate (the odds that a patient reporting depression be judged as depressed was 2.41 times that of a patient who did not report depression). A moderate value (3.31) was obtained for Distress. All symptom DORs were small, except for Suicidal Ideation (4.52).

Similarly, no good or excellent ICCs were obtained (Landis and Koch 1977). Values for Distress (.52), Sadness (.48), Depression (.42), and Suicidal Ideation (.40) indicated fair agreement. The next three highest were Pessimism (.36), Negative Body Image (.30), and Dissatisfaction (.30). Agreement was poor on Self-Dislike (.17), Guilt (.15), and Sense of

Failure (.14). With the exception of Suicidal Ideation (due to high specificity), this order of symptoms provides some support for the idea that less visible symptoms are particularly difficult to detect. However, overlapping confidence intervals indicate minimal differences.

Key Symptoms in Accurate Detection of Depression and Distress

In decreasing order of odds ratios (OR), patient-physician agreement on Pessimism (OR_6.27; 95% confidence interval (CI)_2.94-13.36; p_.000), Negative Body Image (OR_4.27; 95% CI_2.01-9.07; p_.000), Sadness (OR_3.72; 95% CI_1.77-7.82; p_.000), and Dissatisfaction (OR = 3.20; 95% CI_1.51-6.78; p_.002), were retained in the first model, as the most significant correlates of agreement on Depression.

This led to an overall model characterized by a correct classification power of 76.8%. A test of the model against the constant-only model was significant, χ^2 (df = 4, N = 190) = 76.36, p<.001, Nagelkerke R² = .45, indicating that the model statistically distinguished between agreement and non-agreement on Depression.

In decreasing order of ORs, patient-physician agreement on Guilt (OR_4.65; 95% CI_2.18-9.94; p_.000) and Dissatisfaction (OR_3.91; 95% CI_2.02-7.58; p_.000) were retained in the second model, as the most significant correlates of agreement on Distress.

This led to an overall model characterized by a correct classification power of 71.1%. A test of the model against the constant-only model was significant, χ^2 (df = 2, N = 190) = 34.20, p<.001, Nagelkerke R² = .23, indicating that the model statistically distinguished between agreement and non-agreement on Distress.

Empathy Variables Associated with Patient-Physician Agreement

Correlational analyses revealed that patient status, cancer site, patient gender and age showed significant relationships to at least one of the dependent variables. These variables were

integrated as control variables. Physician age and gender were also retained, given their similarity to the patient variables. As expected, the control variables were significantly associated with patient-physician agreement in the regression analyses (data available upon request).

Agreement on Depression was not significantly associated with any of the empathy variables, beyond the effect of controls (Table 2.4). Agreement on Distress was associated with higher-quality relationships (OR_1.81; 95% CI_1.28-2.56; p_.001). Agreement on several symptoms was significantly related to higher CC, perception of higher-quality patient-physician relationships and higher self-efficacy in detecting distress. Agreement on sense of Failure (OR_1.54; 95% CI_1.03-2.32; p_.037) was associated with higher CC. Results approached significance for Guilt (OR_1.61; 95% CI_1.00-2.56; p_.050). Agreement on sense of Failure (OR_1.41; 95% CI_1.02-1.95; p_.040), Dissatisfaction with life (OR_1.95; 95% CI_1.40-2.73; p_.000), Guilt (OR_1.55; 95% CI_1.10-2.18; p_.013), and Self-Dislike (OR_1.56; 95% CI_1.11-2.19; p_.010) were associated with higher-quality relationships, although the ORs are small. Agreement on Sadness (OR_1.92; 95% CI_1.27-2.91; p_.002) was associated with self-efficacy. Contrary to predictions, however, agreement on sense of Failure (OR_.62; 95% CI_.39,-.97; p_.037) and Self-Dislike (OR_.59; 95% CI_.36-.97; p_.039) were associated with lower PT.

Discussion

The present study demonstrates poor oncologist accuracy on patient depressive symptoms, particularly those that are more covert in nature. Accuracy on pessimism, sadness, dissatisfaction with life, and negative body image emerged as key elements when exploring variables associated with accuracy on depression and distress as a whole. Additionally,

physicians who reported higher levels of compassionate care, relationship quality and self-efficacy in detecting distress tended to be more accurate on individual depressive symptoms.

Patient-physician agreement on all symptoms was low. Still, agreement on the intensity of easily recognizable symptoms (sadness, pessimism, negative body image, and dissatisfaction with life) was consistently (though insignificantly) higher than that of less obvious symptoms (self-dislike, guilt, sense of failure). This is in line with the findings reported by Passik et al. (1998). Interesting to note, however, is that overestimation was highest for the former. This may be explained by a tendency to amplify symptoms that are easier to perceive. Indeed, appearances can be misleading; a female patient who has lost her hair will not necessarily hold a negative body self-image. In this study, negative body image was the most overestimated symptom at 39.8%, indicating that oncologists relied too heavily on appearances when rating this symptom. Similarly, Holmes and Eburn (1989) found that nurses were better able to detect distress symptoms such as appearance and tiredness, although these were generally overestimated. Pessimism was the second most overestimated symptom in this study at 36.3%. This corresponds to the findings by Faller et al. (1995), who reported that professional caregivers tended to underestimate the amount of hope held by cancer patients.

An exception was suicidal ideation which, although difficult to detect as indicated by a low sensitivity score, received the highest accuracy scores. This can be explained by an almost-perfect specificity (94.6%).

Recognition of cases was slightly higher for depression than it was for distress, while recognition of non-cases was higher for distress. These results contradict the literature, as the opposite is most commonly found. Still, overestimation was far more frequent for distress. This may be explained by physicians' tendency to rate the DT in a polarized manner (low distress vs.

high distress) – a trend which was not observed on the psychometrically more reliable BDI-SF. Overall though, accuracy was higher on distress than it was on depression and symptoms.

Results suggest that both affective and cognitive symptoms are involved in accurate detection of depression and distress. Accurate detection of pessimism, sadness, dissatisfaction with life, and negative body image accounted for nearly half of the variation in accurate detection of depression. Accurate detection of dissatisfaction with life and guilt contributed the most to accurate detection of distress, although they accounted for less (23%). These may be key symptoms involved in identification of depression and distress amongst adults with advanced cancer. These analyses, however, are still exploratory and should be pursued further.

Support was also found for the hypothesis predicting that aspects of oncologists' empathic ability would be associated with patient-oncologist agreement on depressive symptoms. In accordance with Neumann et al. (2009)'s model of empathic communication, the quality of the patient-oncologist relationship and compassionate care were associated with agreement on several symptoms. Interestingly, these results were found for the symptoms with the lowest levels of patient-physician agreement as measured by the ICC, suggesting that empathy is especially important for evaluating symptoms that are harder to perceive.

Moreover, the results suggest that self-efficacy in detecting patient distress may also play a part, namely in detecting sadness. However, this result only surfaced for one symptom out of eight. One explanation for this is that the scale used may be a better measure of overconfidence than of healthy self-efficacy. A multi-item questionnaire would most likely be needed to reliably measure this construct.

Unexpectedly, perspective taking was associated with inaccuracy on patient sense of failure and self-dislike. Again, this may be due to a gap between the construct which the scale

is meant to measure and that which it actually taps into. Whereas compassionate care captures open-mindedness toward empathy, perspective taking is centred on self-evaluation of empathic skills. The latter scale may inadvertently be measuring overconfidence in one's own empathic skills. Such a phenomenon has been observed amongst pharmacy students; those with poor empathy skills were found to largely overestimate their personal abilities (Austin and Gregory 2007). A performance task would most probably have been a more valid measure.

The present study has several limitations. First, it must be noted that the situation in which oncologists were placed is artificial and may therefore limit the applicability of the results. Perhaps physicians tended to overestimate symptoms simply because the perspective taking task attracted their attention to them. Secondly, the results may be affected by a selection bias, as less than 50% of the contacted physicians participated in the study. Perhaps interest in empathy is related to accuracy on patient distress. Thirdly, the limited sample size combined with the high number of variables likely led to underpowered analyses. The findings should therefore be considered as exploratory in nature. Fourthly, many of the measures have limited reliability due to either low internal consistency (JSPE) or a one-item structure (depressive symptoms, self-efficacy, quality of relationship). Fifthly, some of the empathy variables are not independent and thus may violate the logistic regression assumptions. Consequently, results involving the perspective-taking and compassionate care scores from the JSPE should be considered with caution. Sixthly, it may be argued that between-physician differences explain part of the results. To explore this avenue, we compared agreement rates between physicians and found no significant differences (Figures 2.1 and 2.2). Multilevel analyses with larger samples would be recommended in future studies.

Despite its limitations, this work enriches research on detection of distress in quite a few ways. For one, it points to the importance of using standardized tests to screen for depression, as patient-physician agreement is low on all symptoms. In addition, this study sheds light on some aspects of empathy which may contribute to accurate detection of depression and distress in cancer patients. Teaching empathic skills to clinicians could help them decide whether they should refer patients to psychosocial services when test scores are at a borderline level or unavailable. Once a profile of key symptoms is well delineated, training could be made a lot simpler by focusing on those signs that allow for most efficient detection of depression (and other forms of distress). Moreover, this study adds to current literature on patient-clinician agreement by examining individual symptoms. Previous studies have not offered this level of analysis, and have often presented inappropriate statistical indices. Finally, this study adds to the existing literature by focusing on homogeneous samples that are difficult to recruit, patients and oncologists included. Such properties eliminate potential confounding variables and increase the study's internal validity.

Conclusion

The use of robust indices clearly illustrated oncologists' lack of accuracy on depressive symptoms, especially covert ones. Although the cross-sectional design of this study prevents us from establishing directionality of associations, the findings clearly emphasize the role of empathy in detecting these symptoms. They demonstrate the value of using structured screening instruments and of training physicians in empathic and key-symptom assessment skills. Such measures could significantly enhance the detection and handling of patient depression.

Acknowledgments

This project was funded by the French National Cancer Institute (SHS SPE 2010) and supported by the CHU Sainte-Justine Foundation, the Larry and Cookie Rossy Foundation, and Industrial Alliance. These funding bodies did not participate in design, collection, analysis, or interpretation of data.

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Footnotes

1. $DOR = (\text{sensitivity} \times \text{specificity}) / [(1 - \text{sensitivity}) \times (1 - \text{specificity})]$; 1.5 = small, 2.5 = medium, 4 = large, 10 = very large (Rosenthal 1996).

2. $< .40$ = poor agreement, $.40 - .59$ = fair agreement, $.60 - .74$ = good agreement, $\geq .75$ = excellent agreement (Landis and Koch 1977).

Table 2.1*Sample Description*

Variables	201 Patients			28 Oncologists		
	n (%)	M	SD	n	M	SD
Age		61.97	11.49		46.86	7.77
Gender						
Men	55 (27.4)			10 (35.7)		
Women	146 (72.6)			18 (64.3)		
Years of education / practice		2.64	.91		18.23	8.91
Cancer site						
Breast	91 (45.3)					
Colorectal	42 (20.9)					
Lung	30 (14.9)					
Other	38 (18.9)					
Patient status ^a		1.08	.91			
Physician specialty						
Medical oncology				20 (71.4)		
Radiology				1 (3.6)		
Palliative care				5 (17.9)		
Other				3 (10.7)		
Patient Depression (BDI-SF, 0–24)		3.46	3.33		3.94	3.50
Patient Distress (DT, 0–10)		1.80	1.60		3.07	1.73

Note. ^a0 = normal activity; 1 = some symptoms, but still not fully ambulatory; 2 = < 50% of daytime in bed; 3 = > 50%; 4 = completely bedridden.

Table 2.2*Comparisons Between Oncologist and Patient Ratings*

Measure	M (SD)		r	t (d)	Underestimation (%)	Acceptable Estimation (%)	Overestimation (%)
	Patient	Oncologist					
Depression	3.46 (3.33)	3.94 (3.50)	.29***	1.67 (-.14)	15.9	62.7 ^a	21.4
Symptoms							
A) Sadness	.54 (.72)	.70 (.73)	.31***	2.66** (-.22)	18.4	48.8 ^b	32.8
B) Pessimism	.77 (.88)	.95 (.91)	.22**	2.27* (-.20)	2.2	41.3	36.3
C) Failure	.34 (.69)	.30 (.53)	.08	-.63 (.07)	18.4	63.2	18.4
D) Dissatisfact.	.35 (.57)	.47 (.67)	.18*	2.16 (-.19)	17.9	57.2	24.9
E) Guilt	.25 (.66)	.24 (.57)	.08	-.13 (.02)	11.9	74.6	13.4
F) Self-Dislike	.21 (.47)	.17 (.42)	.09	-.95 (.09)	14.9	73.1	11.9
G) Suicidal Idea	.26 (.63)	.09 (.35)	.29***	-3.65*** (.33)	13.4	82.1	4.5
H) Body Image	.74 (.90)	1.01 (.90)	.18*	3.27** (-.30)	21.9	38.3	39.8
Distress	1.80 (1.60)	3.07 (1.73)	.35***	9.47*** (-.76)	8.5	42.3 ^c	49.3

Note. ^aEvaluations of depression were considered acceptable when situated within 17 points away from the patient's score. This margin is based on an α of .81, calculated for the patient BDI-SF; ^bEvaluations on BDI-SF items were considered acceptable when they exactly matched the patient's score; ^cEvaluations of distress were considered acceptable when situated within 6.3 points away from the patient's score. This margin is based on a test-retest r of .80, reported in a recent validation study of the DT (Tang et al. 2011).

* $p < .05$, ** $p < .01$, *** $p < .001$.

Table 2.3*Accuracy of Oncologists' Ratings*

Measure (base rate %)	Cutoff	Agreement (%)	Se (%)	Sp (%)	κ	DOR	ICC
Depression (51.5)	≥ 3	60.7	68.9 (59.5-77.1)	52.0 (42.3-61.7)	.21 (.14-.34)	2.41 (1.35-4.28)	.42 (.24-.56)
Depressive Symptoms	≥ 1						
A) Sadness (42.6)		41.0	32.5 (.23-.43)	47.3 (38.3-.56.5)	.19 (.08-.32)	0.43 (.24-.78)	.48 (.31-.61)
B) Pessimism (51.8)		39.1	73.5 (64.2-81.1)	44.2 (34.6-54.2)	.18 (.05-.31)	2.20 (1.21-4.00)	.36 (.15-.51)
C) Failure (25.0)		65.0	34.0 (22.4-47.9)	75.3 (67.9-81.6)	.09 (-.05-.24)	1.57 (.79-3.15)	.14 (-.14-.35)
D) Dissatisfaction (30.5)		62.0	49.2 (37.1-61.4)	67.6 (59.5-74.8)	.16 (.02-.30)	2.02 (1.09-3.74)	.30 (.07-.47)
E) Guilt (14.0)		77.0	28.6 (15.3-47.1)	84.9 (78.8-89.5)	.12 (-.04-.28)	2.25 (.90-5.64)	.15 (-.12-.36)
F) Self-Dislike (19.1)		72.9	21.1 (11.1-36.4)	85.1 (78.8-89.8)	.07 (-.08-.21)	1.52 (.62-3.72)	.17 (-.10-.37)
G) Suicide Ideas (17.0)		82.0	20.6 (10.4-36.8)	94.6 (90.0-97.1)	.19 (.02-.36)	4.52 (1.55-13.20)	.40 (.21-.55)
H) Body Image (47.5)		53.5	68.4 (58.5-76.9)	40.0 (31.1-49.6)	.08 (-.05-.21)	1.44 (.81-2.59)	.30 (.08-.47)
Distress (25.9)	≥ 4	64.7	64.3 (45.8-79.3)	64.7 (57.4-71.5)	.17 (.05-.28)	3.31 (1.44-7.61)	.52 (.36-.63)

Note. 95% confidence interval in parentheses; Se = Sensitivity; Sp = Specificity; κ = Kappa statistic. Full statistical information is available upon request.

Table 2.4

Logistic Regression Analysis of Patient-Physician Agreement on Depressive Symptoms as a Function of Empathy Variables

	Sadness	Pessimism	Failure	Dissatisfaction	Guilt	Self-Dislike	Suicidal Ideas	Negative Body Image	Global Depression
Variables	OR (95% CI)								
Quality of relationship	1.90 (.66-1.23)	1.20 (.88-1.63)	1.41* (1.02-1.95)	1.95*** (1.40-2.73)	1.55* (1.10-2.18)	1.56* (1.11-2.19)	.97 (.66-1.42)	1.05 (.78-1.41)	1.345 (.983-1.840)
Compassionate Care	.76 (.52-1.12)	.91 (.63-1.34)	1.54* (1.03-2.32)	.90 (.61-1.33)	1.61 ^a (1.0-2.56)	1.13 (.73-1.74)	1.10 (.68-1.78)	1.25 (.86-1.82)	.887 (.604-1.303)
Perspective Taking	.70 (.45-1.09)	.86 (.56-1.31)	.62* (.39-.97)	1.10 (.71-1.70)	.62 (.37-1.06)	.59* (.36-.97)	.68 (.39-1.20)	.93 (.62-1.40)	.865 (.561-1.334)
Self-efficacy	1.92** (1.27-2.91)	1.35 (.90-2.01)	.87 (.58-1.32)	1.40 (.93-2.12)	.92 (.58-1.49)	1.56 (1.11-2.19)	1.04 (.64-1.68)	1.06 (.72-1.55)	1.412 (.936-2.128)
Model characteristics									
Correct classification (%)	65.1	64.5	70.0	68.5	80.0	72.4	82.0	61.5	67.2
Model χ^2 :	19.09	14.26	24.75	28.42	24.29	26.55	10.66	10.57	21.18
Nagelkerke R ² :	.13	.09	.16	.18	.17	.18	.09	.07	.14

Note. ORs adjusted for site of cancer, patient status, gender and age of physicians and patients.

^ap < .06, *p < .05, **p < .01, ***p < .001.

Figure 2.1

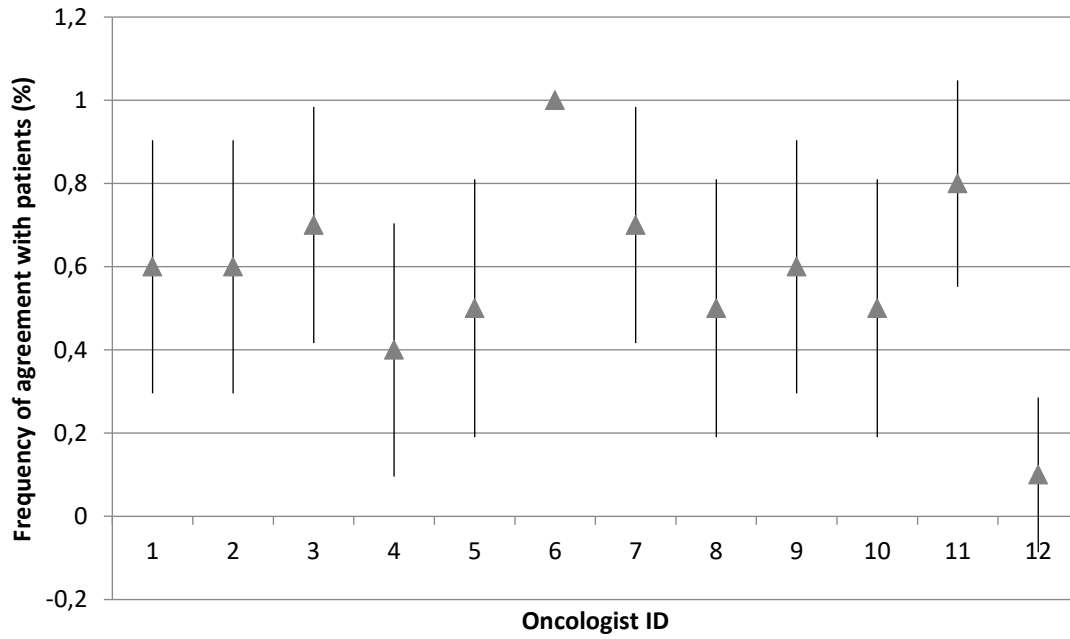


Figure 2.1. Percent frequency of patient-oncologist agreement on depression. Agreement/disagreement was determined according to the BDI-SF cutoff score (3). The figure only features the oncologists who saw ten patients (n = 12). Values are displayed with 95% confidence intervals. Physician #6 was in agreement with all of his patients.

Figure 2.2

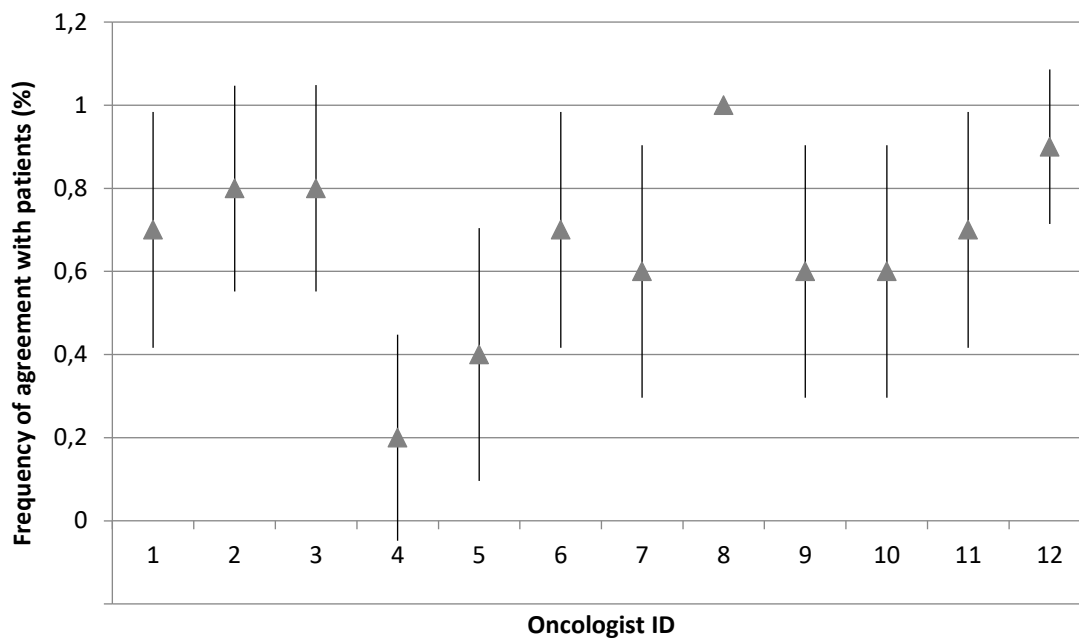


Figure 2.2. Percent frequency of patient-oncologist agreement on distress. Description of data: Agreement/disagreement was determined according to the DT cutoff score (4). The figure only features the oncologists who saw ten patients (n = 12). Values are displayed with 95% confidence intervals.

Chapter 3

Second Article

Comparing two types of perspective taking as strategies for detecting distress amongst parents of children with cancer: A randomized trial

Gouveia, L., Janvier, A., Dupuis, F., Duval, M., & Sultan, S. (2017). Comparing two types of perspective taking as strategies for detecting distress amongst parents of children with cancer: A randomized trial. *PloS one*, 12(4), e0175342.

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Comparing two types of perspective taking as strategies for detecting distress amongst parents of children with cancer: A randomized trial

Running head: Perspective taking to detect distress

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Abstract

Objective: To compare two perspective taking strategies on (i) clinicians' ability to accurately identify negative thoughts and feelings of parents of children with cancer, and (ii) clinician distress. *Methods:* Sixty-three hematology-oncology professionals and nursing students watched a video featuring parents of children with cancer. Participants were randomly assigned to one of two groups. In the *imagine-self* group, they were instructed to imagine the feelings and life consequences which they would experience if they found themselves in each parent's situation. In the *imagine-other* group, they were instructed to imagine the feelings and life consequences experienced by the parents. Parent-clinician agreement on thoughts/feelings was evaluated (standard stimulus paradigm). Clinician distress was also assessed. *Results:* The intervention was effective in manipulating perspective type. The groups did not significantly differ on parent-clinician agreement. Concentrating on personal feelings (imagine-self strategy) was associated with lower agreement when controlling for trait empathy. Clinician distress was higher in the imagine-self group. *Conclusion:* Although the link between perspective type and detection of distress remains unclear, the results suggest that clinicians who highly focus on their own feelings tend to be less accurate on parental distress and experience more distress themselves. *Practice Implications:* This research could potentially improve communication training and burnout prevention.

Introduction

Pediatric cancer is an extremely stressful life event for parents. For many, it is a traumatic experience (Ljungman, Hovén, Ljungman, Cernvall, & von Essen, 2015). Wiener, Kazak, Noll, Patenaude, and Kupst (2015) recently published a set of standards recommending that youth with cancer *and* family members “routinely receive systematic assessments of their psychosocial health care needs.” Adopting a family-centred approach is especially important in pediatric care, since children and their parents significantly influence each other’s psychosocial adjustment to chronic illness (Mullins et al., 2015; Sultan, Leclair, Rondeau, Burns, & Abate, 2015). In addition, addressing parental distress is thought to allow for better parent-clinician collaboration and, ultimately, improved medical care (Spinetta et al., 2002).

Detecting Parental Distress with Empathic Skills

Studies clearly show that clinicians struggle to accurately detect distress in adults with cancer (Chidambaram, Deshields, Potter, Olsen, & Chen, 2014; Keller et al., 2004; Werner, Stenner, & Schüz, 2011), as well as parents of pediatric patients (Patel et al., 2011). These findings advocate for teaching simple communication skills to clinicians (Fukui, Ogawa, Ohtsuka, & Fukui, 2009; Merckaert et al., 2008) and using formal screening tools (Haverman et al., 2013; Leclair, Carret, Samson, & Sultan, 2016). Unfortunately, very little is known on teachable empathic skills that allow for better recognition of negative affect.

As objective and user-friendly screening tests may be, they have limited validity and lack the flexibility of relational abilities. Empathic skills could potentially compensate for these shortcomings. In fact, recent studies have reported positive associations between physician empathy and accurate detection of patient distress (Gouveia et al., 2015; Yagil, Biron, Pat, Mizrahi-Reuveni, & Zoller, 2015).

One factor that explains the lack of research and training in empathic skills is the breadth of the term “empathy.” For the purposes of this paper, we shall refer to “clinical empathy,” defined by Coulehan et al. (2001) as “the ability to understand the [...] [person’s] situation, perspective, and feelings and to communicate that understanding to the [...] [person].” Although empathy is associated with stable personality traits (del Barrio, Aluja, & García, 2004), research suggests that it can also be learned (Bonvicini et al., 2009; Pehrson et al., 2016). The challenge lies in the identification of simple teachable techniques embedded in the broader skill of clinical empathy. One such technique is empathic communication, a style of interaction which is characterized by the demonstration of compassionate understanding. Two studies have found that clinicians who received extensive training in empathic communication were better at detecting distress in adult cancer patients than those who did not (Fukui et al., 2009; Merckaert et al., 2008).

A second way of teaching empathy is through cognitive skills such as perspective taking. To our knowledge, no study has rigorously examined how perspective taking strategies could enhance detection of distress in adults affected by chronic illness. The present study aims to initiate this line of research by comparing two ways of taking a parent’s perspective.

Two Types of Perspective Taking

According to Batson (2009), there are two types of perspective taking. On one hand, taking an *imagine-self* perspective entails imagining oneself in the other’s situation to infer his/her thoughts and feelings. On the other hand, taking an *imagine-other* perspective involves imagining what the other is thinking and feeling, without necessarily concluding that this person experiences life events in the same way as oneself. The first strategy is associated with relatively more self-oriented distress and behaviour, whereas the second is associated with relatively less

personal distress and more altruistic behaviour (Batson, Early, & Salvarani, 1997; Batson et al., 2003; Lamm, Batson, & Decety, 2007). For instance, Lamm et al. (2007) found that participants who had taken an imagine-other perspective, while watching a video of individuals in pain, reported less personal distress (e.g. feeling troubled, low-spirited, alarmed) and more empathic concern (e.g. feeling compassionate, touched, concerned), compared to participants who had adopted an imagine-self perspective.

One group of researchers has examined the relationship between perspective type and accurate detection of distress. Lobchuk and colleagues found that informal caregivers who adopt an imagine-other perspective tend to show less discrepancy with cancer patients on symptom ratings, compared to those who adopt an imagine-self perspective (M. M. Lobchuk, Degner, Chateau, & Hewitt, 2006; Michelle M. Lobchuk, McClement, Daeninck, Shay, & Elands, 2007; Michelle M. Lobchuk & Vorauer, 2003). Their studies have important methodological limits, including a poor measure of caregiver accuracy and a theoretical error in the imagine-other instructions. Nonetheless, their findings suggest that the imagine-other perspective could lead to higher accuracy. Batson's research sheds light on the mechanism(s) involved. One way the imagine-self perspective could evoke self-oriented distress is by blurring the boundary between mental representations of self and other. In support of this idea, neuroimaging studies have found that the imagine-self and imagine-other perspectives show differences in brain activation in areas associated with self-other differentiation (Jackson, Brunet, Meltzoff, & Decety, 2006; Lamm et al., 2007; Ruby & Decety, 2001, 2004). Other studies have found that the imagine-self perspective is associated with more self-related thoughts (Davis et al., 2004) and higher perception of self-other overlap (Myers, Laurent, & Hodges, 2014). If the imagine-other perspective does in fact allow for better self-other differentiation than the imagine-self

perspective, then it should lead to more accurate perception of the other's thoughts and feelings. A second explanation could be that personal distress interferes with perception, as suggested by research in emotion recognition (Gery, Miljkovitch, Berthoz, & Soussignan, 2009; Lampic, von Essen, Peterson, Larsson, & Sjoden, 1996; Schmid & Schmid Mast, 2010). Since the imagine-other perspective has been associated with relatively less personal distress and is thought to allow for better self-other differentiation, it seems more appropriate than the imagine-self perspective for detecting distress in parents affected by cancer.

Objectives

Our first objective was to compare two types of perspective taking on clinicians' ability to accurately infer parents' negative thoughts and feelings. We hypothesized that clinicians taking an imagine-other perspective would show higher accuracy than those taking an imagine-self perspective. Our second objective was to verify previous findings linking the imagine-self perspective with relatively more personal distress than the imagine-other perspective (Batson et al., 1997). An exploratory objective was to examine whether clinicians' personal distress could be tested as a possible mediator of the relationship between perspective type and clinician accuracy. The three objectives were successfully addressed in the order described above.

Methods

Development of the Stimulus Video

A stimulus video based on interviews conducted with parents of children with cancer was developed for the study. Five parents were recruited at the Sainte-Justine UHC. To ensure sufficient content, parents with relatively long cancer journeys were selected. Their child needed to be at least one year post-diagnosis and five years of age or older. Parents needed to be fluent in French. Two-hour filmed interviews were scheduled for parents who accepted to participate.

The questions were semi-structured and covered the parent's cancer journey and emotional experience (see Appendix B for interview questions).

Segments of three interviews were selected for the final video according to ease of communication during the interview and variety of negative thoughts and feelings reported post-interview. To increase ecological validity, parents with different expressivity scores on the Berkeley Expressivity Questionnaire (Gross & John, 1995, 2013) were selected.

Since using the original videos would have biased the results, the selected segments were slightly modified and reproduced by professional actors at the hospital's medical simulation centre. To ensure valid reproductions, the actors studied the recordings, in addition to fully typed scripts. They were given the thoughts and feelings reported by the parents at particular time points, and were asked to replicate these parts as close to the original as possible. Each segment was filmed several times to allow for feedback on tone of voice, facial expressions, posture, mannerisms, etc. The actors signed a confidentiality form before accessing the material.

The final stimulus video is 27 minutes in duration. The first part is composed of six segments, where the parents share parts of their story. The second is composed of 18 segments, where they discuss emotional aspects of their journey.

Recruitment

Professionals in pediatric hematology-oncology (physicians, nurses, occupational therapists, physiotherapists and social workers) and nursing students were recruited from April to December 2015. Professionals were selected from a registry of 92 health care professionals at the Charles-Bruneau Cancer Centre (Sainte-Justine UHC). An electronic letter describing the study and offering possible participation dates was sent to them by the principal investigator. An announcement containing similar information was posted throughout the department. The

nursing students were recruited through the Faculty of Nursing Sciences at the University of Montreal. This was achieved through in-class announcements and distribution of handouts. To be eligible, participants needed to not have collaborated on the project in any way. Professionals needed to have been practising in hematology-oncology on a regular basis, for a minimum of one year.

Design Overview

A quasi-experimental design with two groups and one post-test evaluation was developed for the present study. After signing consent and confidentiality forms, participants watched the stimulus video. Right before the viewing, each participant received instructions intended to induce one of the two perspective types: imagine-self or imagine-other. Instructions for the imagine-self group read as following: ‘In the following minutes, you will watch interviews featuring three parents of children with cancer. While viewing the video, **try to imagine how you would feel if you were living the same thing as each of these parents and how this would affect your life.**’ Alternately, participants in the imagine-other group were instructed to ‘**try to imagine how each parent feels about his/her story and how this has affected their lives.**’ Random stratification was employed to form the imagine-self and imagine-other groups on the basis of two lists (nursing students versus hematology-oncology professionals). Participant names were ordered according to scheduled date of participation. For each list, assignment of participants to the imagine-self and imagine-other groups was done in alternate manner. This procedure was done separately for men and women so that the groups could be balanced on gender.

During the second part of the video, participants were reminded of their instructions and parent-clinician agreement on the content of negative thoughts and feelings was evaluated

through a self-report method (see Measures). Participants then completed a questionnaire measuring their personal distress. Participation lasted approximately one hour. Additional take-home questionnaires measuring trait empathy were given to them. After returning the questionnaires, participants received a compensation in the form of monetary gifts and donations to parent care services, for a total of 50\$ per participant. The participants were also offered free meals.

This protocol was approved by the Sainte-Justine UHC Ethics Committee (#4016) and the University of Montreal Ethics Committee for Health Research.

Measures

Effectiveness of perspective taking manipulation.

Effectiveness of the experimental manipulation was evaluated post-intervention, as in Batson's initial study (Batson et al., 1997). For assessment of the imagine-self perspective, participants were asked to rate how much they had concentrated on their own feelings, as if they were personally experiencing the stories told by the parents. For assessment of the imagine-other perspective, participants rated how much they had concentrated on the parents' feelings. Both answers were rated on scales ranging from 0 (not at all) to 10 (very).

Parent-clinician agreement on negative thoughts and feelings.

Parent-clinician agreement on the parents' thoughts and feelings was measured using the *standard stimulus paradigm of empathic accuracy* (Marangoni, Garcia, Ickes, & Teng, 1995). Post-interview, the parents had been asked to watch their video and record every thought and feeling they remembered having. This was done using a standardized thought/feeling recording form adapted from the original version used in Marangoni et al. (1995). Each time the parent remembered having had a thought or feeling, they were to stop the tape and record the time, the

specific content of the thought/feeling, and its valence (positive, neutral, or negative). Instructions on the form are meant to minimize biases due to self-censorship (see Appendix A for a copy of the form).

When showing the final video to the participants, the research assistant stopped it at specific time points where the parents had reported thoughts or feelings. The participants then had to infer the content of each thought/feeling and record it on another standardized thought/feeling inference form (Marangoni et al., 1995; see Appendix A). For the present study, the tape was stopped at 18 feelings or thoughts, 15 of which were negative in valence.

As in the standard paradigm (Marangoni et al., 1995), four independent raters (trained psychology students blind to group assignment) rated the extent to which each inference was similar to the actual thought/feeling reported by the parent. The rating scale ranged from 0 to 2, where 0 = ‘essentially different content,’ 1 = ‘similar, but not the same, content,’ and 2 = ‘essentially the same content’ (Ickes & Hodges, 2013). Scores for each inference were averaged across raters. A mean value of .75 was obtained for inter-rater reliability, suggesting a substantial level of agreement (Landis & Koch, 1977). The total parent-clinician agreement score was computed by dividing the total sum of inference scores by the maximum points, multiplied by 100.

Personal distress.

Post-intervention, participants completed the Emotional Response Scale (ERS; Batson et al., 1997; Coke, Batson, & McDavis, 1978; Appendix A). The test measures personal distress and empathic concern in reaction to a person in need/distress. Of particular interest for this study is the Personal Distress subscale, composed of eight items/emotions (alarmed, grieved, troubled, distressed, upset, disturbed, worried, and perturbed) rated on a scale of 1 to 7. Principal

components analyses support the two-factor structure of this questionnaire (Batson, Fultz, & Schoenrade, 1987). In this study, Cronbach alphas of .80 and .84 were obtained for Empathic Concern and Personal Distress, respectively.

Clinician empathic traits.

Participants completed the Interpersonal Reactivity Index (IRI; Davis, 1983; Guttman & Laporte, 2002; Appendix A), a measure of individual differences in empathy composed of four factors: Empathic Concern, Perspective Taking, Personal Distress and Fantasy. The subscales have demonstrated good internal consistency, with Cronbach alphas ranging from .70 to .78 (Davis, 1980). They have also demonstrated good construct validity (Davis, 1983; Lawrence, Shaw, Baker, Baron-Cohen, & David, 2004; Yarnold, Bryant, Nightingale, & Martin, 1996).

Statistical Analyses

In preliminary analyses, the effectiveness of the perspective taking manipulation was examined. To determine whether relative levels of concentration on personal feelings and parent feelings varied as a function of experimental group, a repeated measures factorial ANOVA was performed with experimental group (imagine-other vs. imagine-self) as the between-group factor, type of feelings attended to (personal feelings vs. parent feelings) as the repeated measure, and level of concentration as the dependent variable.

For the first objective, an independent samples t-test was performed to compare the experimental groups on parent-clinician agreement on negative thoughts/feelings. Clinician empathic traits were added as control variables in ANCOVAs and in additional correlation analyses.

For the second objective, the groups were compared on personal distress in an independent samples t-test.

Previous studies comparing the emotional responses associated with the two types of perspective taking have reported moderate to large effect sizes (Batson et al., 1997; Lamm et al., 2007). Power analyses (Faul, Erdfelder, Albert-Georg, & Buchner, 2007) indicated that a sample of approximately 60 participants would achieve 80% power for a Cohen's d of .60 on our first objective, representing a between-group difference of 10% on parent-clinician agreement.

Analyses for both studies were performed through IBM SPSS Statistics 20 and an alpha level of .05 was set for statistical significance.

Results

Seventy-five participants were assessed for eligibility (see Figure 3.1 for participant flow chart). Six refused to participate. Six additional participants dropped out before the beginning of the study for reasons related to time constraints and/or lack of motivation. The difference between these individuals and those who participated are unknown. A total of 29 hematology-oncology professionals and 34 nursing students participated in this study. Out of the 63 participants, 53 (84.1%) were female and 50 (79.4%) were white. Most were either nurses or nursing students (77.8%; see Table 3.1 for sample description).

Effectiveness of Perspective Taking Manipulation

In the repeated measures ANOVA, a significant interaction effect was found for group and type of feeling, $F(1, 61) = 9.27, p < .01$, with a medium effect size (partial $\eta^2 = .132$; Figure 3.2). Tukey analyses showed a significant difference in clinicians' level of concentration on personal feelings between the imagine-self group ($M = 6.32, SD = .40$) and the imagine-other group ($M = 4.69, SD = .40$), $p < .05$. The groups did not significantly differ on level of concentration on parent feelings.

Main Outcomes

Parent-clinician agreement on negative thoughts and feelings.

No significant difference was found between the imagine-self group ($M = 53.20$; $SD = 8.70$) and the imagine-other group ($M = 56.32$; $SD = 8.76$) on parent-clinician agreement on negative thoughts and feelings, $t(61) = -1.41$, $p = \text{n.s.}$ Similar non-significant results were found when controlling for the effect of empathic traits in ANCOVAs.

In correlational analyses performed across groups, higher concentration on personal feelings was associated with lower parent-clinician agreement when controlling for three of the four empathic traits. Moderate partial correlation values of $r(55) = -.29$, $-.27$, and $-.27$ ($p < .05$) were obtained when controlling for IRI Empathic Concern, Personal Distress, and Fantasy, respectively. The partial correlation obtained when controlling for Perspective Taking was slightly lower, $r(55) = -.22$, $p = \text{n.s.}$

Clinician personal distress.

The average level of clinician personal distress, as measured by the ERS, was significantly higher in the imagine-self group ($M = 3.03$, $SD = 1.24$) than in the imagine-other group ($M = 2.47$; $SD = .19$), $t(55) = 2.02$, $p < .05$ (Figure 3.3), with a large difference ($d = .625$). Note that since Levene's test indicated unequal variances ($F = 4.23$, $p = .044$), degrees of freedom were adjusted from 61 to 55.

No significant difference on clinician empathic concern, as measured by the ERS, was found between the imagine-self group ($M = 4.15$, $SD = 1.30$) and the imagine-other group ($M = 4.01$, $SD = 1.32$), $t(61) = .45$, $p = \text{n.s.}$

In additional analyses performed across groups, concentration on personal feelings and personal distress were found to be significantly correlated at a moderate level, $r(61) = .25$, $p <$

.05. Personal distress and agreement on parent thoughts and feelings were not found to be significantly correlated, $r(61) = .01, p = \text{n.s.}$

Discussion

The present study compared two types of perspective taking as clinical strategies for detecting distress in parents of children with cancer. Supporting the experimental manipulation's effectiveness, clinicians instructed to adopt an imagine-self perspective reported higher levels of concentration on personal feelings compared to clinicians instructed to adopt an imagine-other perspective. In contrast to our predictions, the imagine-self group did not show significantly lower agreement with parents on their negative thoughts and feelings. However, correlational analyses showed a negative association between parent-clinician agreement and level of concentration on personal feelings (imagine-self strategy). Replicating previous findings, clinicians in the imagine-self group reported higher levels of personal distress.

Our main hypothesis stipulated that clinicians instructed to adopt an imagine-other perspective would show higher agreement with parents on their thoughts and feelings, compared to clinicians instructed to adopt an imagine-self perspective. Although this was not supported by the analyses, we estimated that only seven more participants would have been needed to obtain a significant difference with the same effect size. Moreover, the intervention *was* successful at manipulating the degree to which clinicians concentrated on their personal feelings, which in turn was associated with lower agreement when controlling for trait empathy. Since concentrating on personal feelings is an imagine-self strategy, this finding suggests an indirect link between the imagine-self perspective and poorer accuracy. Still, it is important to examine why these correlational results did not translate into a significant group difference. Perhaps the intervention was insufficiently effective. The extent to which clinicians

concentrated on their personal feelings may have largely depended on their own preferences, in addition to experimental manipulation. For the purpose of replication, the present study uses Batson's methodology in its simple form. However, future studies could increase the effectiveness of the intervention by using a procedure that constantly reminds participants of their instructions. For example, thought/feeling reporting forms could be slightly altered. The imagine-self form could read, 'If I were in that person's situation, I imagine that I would think/feel...' before each inference. Alternately, the imagine-other form could read, 'I imagine that this parent thinks/feels...' We would expect this to considerably increase the chances of finding a significant group difference in parent-clinician agreement. Experimental studies with larger sample sizes and more elaborate interventions may eventually indicate a causal relationship between perspective type and clinician accuracy.

Previous findings on the emotional outcomes of perspective taking were replicated by the present study (Batson et al., 1997; Lamm et al., 2007). As predicted, clinicians in the imagine-self group reported more personal distress than did those in the imagine-other group. The greater amount of variance in the imagine-self group could be explained by possible conflicts between the imagine-self instructions and clinicians' preferences. When asked which strategy they most frequently used to infer parents' experience, 83% reported usually relying on observed parent characteristics as compared to 27% usually relying on their own emotions. While some studies have linked clinical empathy with compassion fatigue and burnout, others have reported positive associations with psychological well-being and work satisfaction (Lamothe, Boujut, Zenasni, & Sultan, 2014; Picard et al., 2016; Zenasni, Boujut, Woerner, & Sultan, 2012). The distinct emotional reactions associated with the imagine-self and imagine-other perspectives provide a potential explanation for these discrepant findings. Perhaps

empathy does lead to excessive personal distress when a clinician relies too heavily on an imagine-self perspective. Alternately, an imagine-other perspective may play a protective role against distress, without compromising accuracy or empathic concern. This idea resembles the common distinction between sympathy and empathy (Hojat, Spandorfer, Louis, & Gonnella, 2011; Nightingale, Yarnold, & Greenberg, 1991). Similar to previous findings (Batson, 2009; Myers et al., 2014), no significant group difference was found on empathic concern. This finding suggests that complete emotional detachment is not necessary for protecting clinicians from detrimental psychological distress.

In contrast to our predictions, personal distress showed no correlation with parent-clinician agreement. These results do not suggest that personal distress could mediate the hypothesized link between perspective type and parent-clinician agreement. Perhaps a more plausible mediator is self-other differentiation. In this case, poor differentiation, rather than high personal distress, would explain why clinicians who were more focused on their personal feelings (imagine-self strategy) tended to obtain lower parent-clinician agreement scores. As stated earlier, the two types of perspective taking show neurological and cognitive differences associated with self-other differentiation (Davis et al., 2004; Jackson et al., 2006; Lamm et al., 2007; Myers et al., 2014; Ruby & Decety, 2001, 2004). A relatively feasible goal for future studies would be to examine whether the activation of specific brain areas mediates the relationship between perspective type and parent-clinician agreement.

Concluding that the imagine-self perspective is a categorically useless strategy would be unempirical. According to Batson, imagining oneself in another's shoes (i.e. the imagine-self perspective) most likely acts as a useful "stepping stone" to understanding the other's personal experience with limited information (Batson, 2009). However, previous findings suggest that

self-other differentiation is important, at least as a subsequent step in the empathic process. Such oscillation between shared and differentiated representations might be the optimal perspective taking strategy. Although the imagine-other instructions allow for this oscillation, they do not specify it. In future studies, it would be pertinent to have a third group of participants imagine the other as being both similar and dissimilar to them. This approach corroborates Carl Rogers' conceptualization of empathy which he defined as "the perception of the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person, but without ever losing the 'as if' condition" (Rogers, 1959).

Study Limitations

There are a few limits to this protocol. First, the effectiveness scales used in the present study have yet to be formally validated. These were selected for the purpose of replicating Batson's original protocol. To our knowledge, no other measures of imagine-self and imagine-other perspective taking have been developed. Future investigations could avoid such a limitation by relying more heavily on experimental methods. Alternately, perspective type could be inferred through a mixed methods approach. In the paradigm proposed by Davis et al. (2004), participants retrospectively record the thoughts they had while watching the video, which are then coded as self- or other-related. Such a method could be used to examine how clinician thought content is related to parent-clinician agreement. Secondly, clinicians who chose to participate were most probably more interested in empathy compared to those who did not. Since motivation is an important part of empathy, the results may not be representative of health care professionals as a whole. Thirdly, one could criticize the stimulus video's validity, given that the actual parents are not featured in it. However, any effect caused by differences between

the two versions was controlled for, as the same video was shown to all participants. Moreover, such an effect would most likely cause a conservative ceiling effect, since the major challenge for the actors was moderating the expression of emotions they intended to convey. Failing at this would facilitate the task. This may have happened in the present study, and could partially explain the lack of between-group difference on our main outcome. Finally, many participants reported difficulty in generating words to describe the feelings they perceived in the parents. However, offering a list of words might render the task too easy (Ickes, 1993). To deal with this challenge, a little extra time was allowed for participants to finish writing their answers.

Conclusion

With the application of basic socio-cognitive theory and methodology in the oncology setting, the present study contributes important findings on the clinical utility of two perspective taking strategies for detecting distress in parents of children with cancer, as well as other persons affected by cancer. Although parent-clinician agreement on parental distress was not found to significantly differ between experimental groups, the results suggest that the imagine-other perspective is a generally more adaptive clinical tool than the imagine-self perspective. Being associated with higher personal distress, the imagine-self perspective may place clinicians at greater risk for professional burnout. In addition, the imagine-self perspective was not found to yield any advantages for detection of distress. On the contrary, it was associated with poorer parent-clinician agreement when measured as level of concentration on personal feelings. The findings point to self-other differentiation as a plausible key strategy for enhancing clinician accuracy and psychological well-being.

Practice Implications

This research helps broaden the repertoire of trainable empathic skills and strategies for detecting distress. A recent multi-centre survey conducted in the United Kingdom indicates that professionals in cancer care are eager to learn more about emotion recognition and management as part of psychological training and support (Laffan, Daniels, & Osborn, 2015). The present study suggests that emotion identification could possibly be improved by practising shared attention between self and other as separate mental representations.

Acknowledgments

We would like to thank the professionals, the students, and the parents who participated in this study. In addition, we thank the Sainte-Justine Mother and Child Simulation Centre, the actors, and Dr. Ahmed Moussa for their implication in the production of the stimulus video. We thank Dr. Alain Legault, Pr. Anne-Marie Martinez, Marie-Claude Charrette, and Manon Laviolette for contributing to the recruitment process. We thank Martin Lamothe, Marie-Pier Bilodeau, Lancelot Legendre-Courville, and Lydia Ouchene, who served as raters for analysis of parent-clinician agreement. Finally, we would like to thank Willow Burns for her help with reviewing the text.

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Table 3.1*Sample Description*

Variables	n (%)	M	SD
Age		30.59	11.03
Gender			
Men	10 (15.9)		
Women	53 (84.1)		
Ethnicity			
White	50 (79.4)		
African	5 (7.9)		
Haitian	3 (4.8)		
Asian	2 (3.2)		
South American	2 (3.2)		
Arab	1 (1.6)		
Profession			
Nurse	21 (33.3)		
Nursing student ^a	28 (44.4)		
Medical Doctor	7 (11.1)		
Occupational Therapist	3 (4.8)		
Physiotherapist	3 (4.8)		
Social Worker	1 (1.6)		
Experience in oncology ^b		3.80	5.98
Experience with parents ^b		6.13	9.06

Note. ^a Six nursing students already possessed a technical degree in nursing.

^b Experience is represented in years.

Figure 3.1

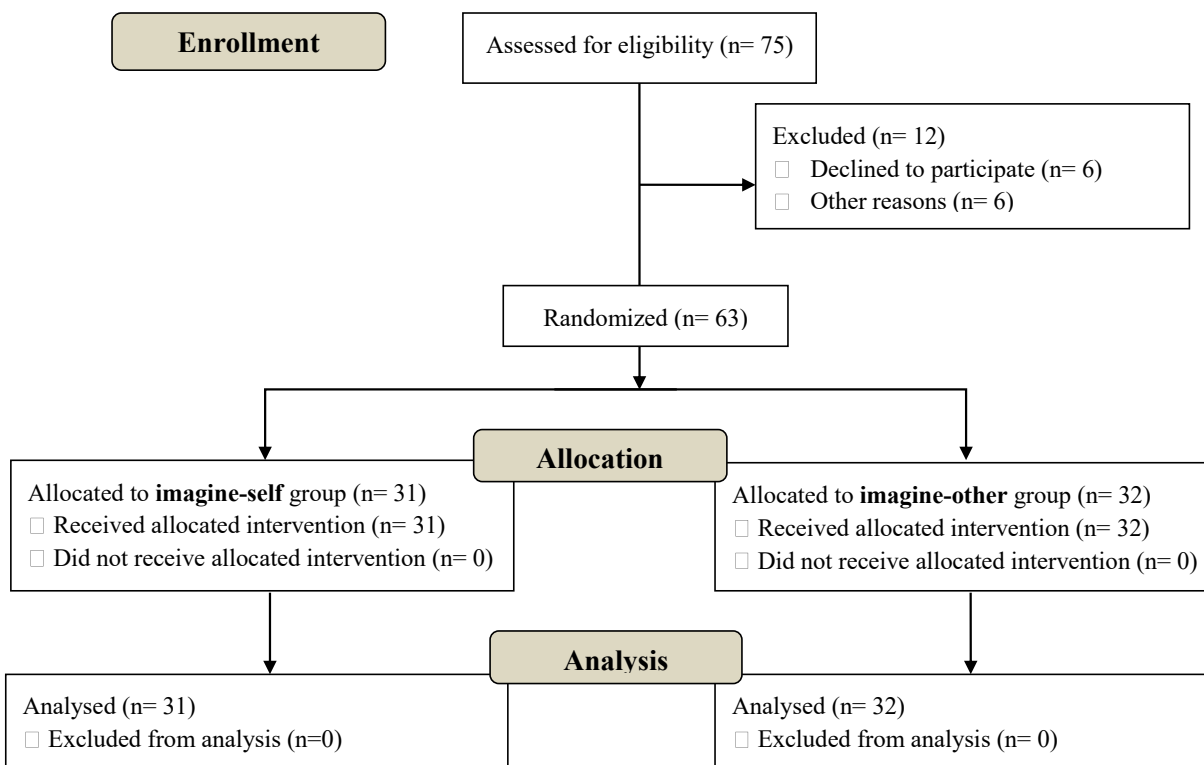


Figure 3.1. Participant flow chart following Consolidated Standards of Reporting Trials Guidelines.

Figure 3.2

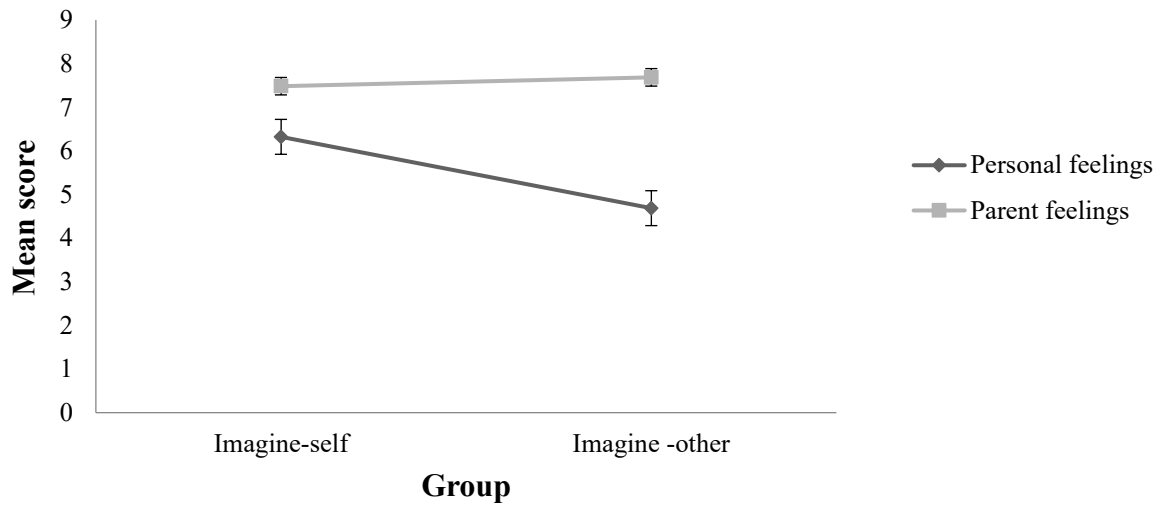


Figure 3.2. Clinicians' level of concentration on personal and parent feelings as a function of experimental group ($p < .01$). Error bars represent standard deviations.

Figure 3.3

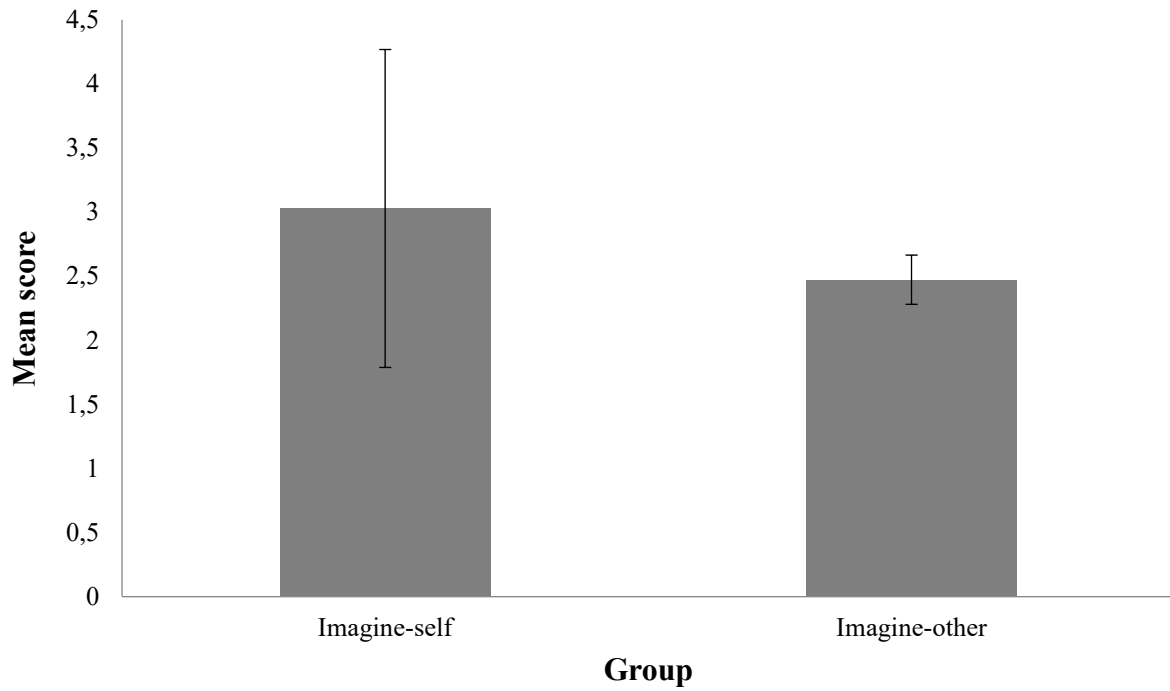


Figure 3.3. Mean level comparison of clinician personal distress between the two experimental groups ($p < .05$). Error bars represent standard deviations.

Chapter 4

General discussion

The present thesis proposes a new direction for research on detection of distress amongst persons affected by cancer. Previous research findings suggest that oncology professionals often struggle to accurately recognize the presence of distress in adult patients. As a result, many patients and family members who would benefit from psychosocial assistance are not offered such services. The present thesis project aimed to clarify the problem and to identify empathic skills that could potentially contribute to more accurate detection of distress. To begin, we expanded on existing research by examining physician ability to detect depression in patients with advanced cancer. This was achieved through dyadic analysis of patient-physician agreement on specific symptoms. To continue, we examined the relationship between clinician empathy and detection of distress in persons affected by cancer. Although much progress has recently been made in the implementation of screening tests, only a few studies have examined empathic skills as a complementary solution. In the first study, we explored the relationship between physician-reported aspects of empathic ability and physician accuracy on patient depressive symptoms. In the second study, we focused on a specific and largely neglected skill: that of perspective taking. By integrating social psychological theory and methodology in the study design, we were able to compare the differential effects of two perspective taking strategies on clinician ability to infer negative thoughts and feelings experienced by parents of children with cancer. Although the results are preliminary in nature, the subject and method of our study open a new and largely viable avenue for research on empathy training as a means for improving detection of distress in persons affected by cancer.

The following discussion begins with a synthesis and integration of our research findings on clinician ability to detect specific symptoms in adults with advanced cancer (objective 1), and on empathy as a tool for detecting distress in persons affected by cancer (objective 2). It clarifies how the first study's results on clinician empathy relate to the elaboration of a more specific intervention study on perspective taking. The second part of the general discussion presents a series of reflections on the theoretical implications for basic research in social psychology, as well as the theoretical and practical implications for the development of empathy training programmes aimed at improving detection of distress in persons affected by cancer. The third part of the discussion highlights important strengths and limitations, as well as future directions for this line of research. Lastly, a final part concludes on the essential contributions of this work.

Synthesis and Integration of Research Findings

Clinician ability to detect specific symptoms.

The first objective of the present thesis was to evaluate clinician ability to detect distress in persons affected by cancer. This was primarily addressed in the first article, which examined physician ability to detect depressive symptoms experienced by adults with advanced cancer. An important aim of this study was to avoid common methodological limitations by using appropriate statistical indices to measure patient-physician agreement. We found that physicians struggled to accurately perceive a variety of cognitive and affective symptoms of depression. These results replicate previous findings in a new population, indicating that clinicians often make inaccurate judgments on the presence or absence of distress (Cepoiu et al., 2008; Mitchell, Hussain, Grainger, & Symonds, 2011; Werner, Stenner, & Schüz, 2011). We also found that physicians had more difficulty recognizing the more covert cognitive and affective symptoms

of depression such as self-dislike, guilt, and sense of failure. Since these symptoms serve as essential criteria for diagnosing depression in cancer patients (American Psychiatric Association, 2013; Trask, 2004), we concluded that detection of depression and general distress may be improved by empathy training aimed at facilitating recognition of covert symptoms, in addition to routine administration of brief screening tools. The following subsection describes the second part of this thesis, which examined empathic skills as a plausible solution to inaccurate detection of distress in persons affected by cancer.

Empathic skills and perspective taking for detection of distress.

The second aim of this thesis was to identify empathic skills that might allow for more accurate detection of distress in persons affected by cancer. In the first article, the relationship between self-reported empathy variables and physician ability to detect distress was examined. We found that physicians' compassionate care, quality of relationship with patients, and sense of self-efficacy in detecting patient distress were significantly associated with patient-physician agreement on covert depressive symptoms. These findings justified the need for more rigorous research on specific and teachable empathic skills which could contribute to the detection of subtle signs and symptoms of distress. Important to note is that, in contrast to other variables, self-reported perspective taking ability showed a negative association with patient-physician agreement. We hypothesized that this might be explained by either physicians' overestimation of their perspective taking skills or the questionnaire's low internal consistency. Alternately, the relationship between perspective taking and patient-physician agreement may be moderated by the type of perspective taking. This question was addressed in the second article, by examining the differential effects of two perspective taking strategies (imagine-self and imagine-other; Batson, 2009) on clinician ability to infer negative thoughts and feelings experienced by parents

of children with cancer. The standard stimulus paradigm (Marangoni, Garcia, Ickes, & Teng, 1995), a well-established method in interpersonal research, was employed to measure the level of parent-clinician agreement on thoughts and feelings. No significant difference between clinicians instructed to adopt an imagine-self perspective and those instructed to adopt an imagine-other perspective was obtained on parent-clinician agreement. However, we found that agreement tended to be lower amongst clinicians who reported being more focused on their own feelings, when controlling for trait empathy. Concentrating on personal feelings is a central aspect of the imagine-self perspective. In fact, clinicians in the imagine-self group did report being more highly concentrated on personal feelings, compared to clinicians in the imagine-other group. These results suggest that, for certain clinicians, relying on an imagine-self strategy may lead to lower accuracy.

Although the underlying mechanisms remain unclear, our findings did not support the idea that personal distress could mediate the hypothesized link between perspective type and clinician accuracy. Indeed, we found no association between personal distress and parent-clinician agreement. As discussed in the third chapter of this thesis, the negative correlation between parent-clinician agreement and the imagine-self strategy of concentrating on personal feelings may be better explained by a blurring of boundaries between the mental representations of self and other. Indeed, studies examining neurological activity and thought content indicate that individuals who adopt an imagine-self perspective tend to experience lower self-other differentiation (Davis, 2004; Jackson, Brunet, Meltzoff, & Decety, 2006; Lamm, Batson, & Decety, 2007; Myers, Laurent, & Hodges, 2014; Ruby & Decety, 2001, 2004). One may speculate that this poor differentiation might lead to higher personal distress, in addition to poorer accuracy. This would explain our finding that clinicians in the imagine-self group

reported more personal distress than did those in the imagine-other group. Taken together, our findings suggest that imagine-other perspective taking is an overall more adaptive clinical strategy for detecting distress in persons affected by cancer. Theoretical and practical implications of these findings are discussed below.

Implications of the Present Thesis

The present thesis contains findings that are pertinent to both basic and applied areas of psychology. The following two subsections summarize the theoretical and practical implications for social psychological research on empathy and perspective taking, as well as clinical training in oncology.

Theoretical implications for basic research on empathy and perspective taking.

Existing research on perspective taking strongly indicated that the imagine-other and imagine-self perspective taking types had different effects on the observer's personal distress and altruistic behaviour. However, little was known about the differential effects of perspective type on emotion and thought identification. The present thesis introduces a new line of research aimed at filling this gap. Our preliminary findings suggest that an imagine-self perspective, characterized by the cognitive act of concentrating on personal feelings, could possibly hinder one's ability to accurately detect distress. Moreover, our results serve as a replication of previous findings linking the imagine-self perspective with higher levels of personal distress in the observer. This supports Batson's original theory, which stipulates that an imagine-self perspective leads to higher personal distress than an imagine-other perspective. Similar to previous findings, we found no significant difference on empathic concern.

Additional studies and randomized controlled trials with larger sample sizes and more elaborate interventions are needed to verify whether the imagine-self perspective does in fact

lead to significantly less accurate perception of distress. Future investigations should consider the possibility that this relationship may be moderated by other factors. For example, the effect of the imagine-self perspective on accuracy may vary as a function of whether or not it is used in combination with an other-oriented perspective. Perhaps alternating between an imagine-self and an imagine-other perspective is the optimal strategy. As discussed in the second article, it is thought that the former can serve as a useful stepping stone to understanding the other's perspective (Batson, 2009). Just as empathy and sympathy are related, the imagine-other and imagine-self perspectives might function interdependently. In fact, the imagine-other perspective does not exclude the imagine-self strategy. An observer following the imagine-other instructions could choose to imagine the other's experience by imagining their own personal experience (imagine-self strategy). Thus, the imagine-other perspective allows for a whole array of inference strategies. Future investigations may benefit from conceptualizing and operationalizing the imagine-other perspective with greater precision.

Another possible moderator of the relationship between perspective type and detection of distress is personality. Individuals with antisocial traits, for instance, may show better emotion identification when using an imagine-self perspective. In fact, Decety, Chen, Harenski, and Kiehl (2013) found neurological evidence suggesting that the imagine-self perspective was more effective than the imagine-other perspective at evoking a typical empathic response in persons with clinical levels of psychopathy. Thus, the potential effect of perspective type on detection of distress may depend on various personal and contextual factors. The present thesis serves as part of the basis for this new multifaceted line of research.

Theoretical and practical implications for clinical training in oncology.

Some of our findings suggest that the acquisition of empathic skills such as perspective taking could help clinicians detect those cognitive and affective symptoms which are more difficult to perceive. The first study highlighted the need for better clinical training in detection of distress. As expected, physicians showed very poor agreement with patients on the less visible symptoms of depression. The fact that empathy variables were associated with higher agreement on these same symptoms provides some support for the utility of empathy training. The findings from our second study suggested that an imagine-self strategy was negatively associated with clinicians' ability to accurately detect negative thoughts and feelings. Thus, more elaborate intervention studies should be developed to test for any causal effect. Such trials will undoubtedly influence communication training for professionals in oncology and other health fields. The practical value of this work extends beyond the potential impact of perspective type on detection of distress. As indicated by our finding that perspective type had a significant effect on clinicians' personal distress, this research has important implications for the protection of their psychological well-being. Professional burnout is associated with a wide array of negative repercussions on job performance and empathy (Zenasni, Boujut, Woerner, & Sultan, 2012). Hence, this aspect alone could justify the integration of imagine-other training in initial and continuing education. Future investigations should assess clinician distress through various measures of distress and well-being.

Limitations

A first limitation is the small size of our samples. This factor may decrease the generalizability of our results. It might also have prevented us from finding a significant effect of the perspective taking intervention on clinicians' ability to detect parent distress. A second

important limitation of this research is self-selection bias. Since many of the solicited clinicians and students did not participate in our studies, the final samples are unlikely to be fully representative of the target populations. Individuals who chose to participate likely had a higher-than-average interest for the subject of empathy. Valuing the welfare of a person in need has been experimentally associated with increased empathic concern and perspective taking (Batson, Eklund, Chermok, Hoyt, & Ortiz, 2007). Consequently, the participants may have had relatively high empathic ability due to high motivation. One may further speculate that, pre-intervention, the participants in our second sample were generally skilled at adopting an imagine-other perspective. In fact, a large majority of participants (83%) reported using the imagine-other strategy more frequently than the imagine-self strategy in their daily work. Thus, we have reason to think that self-selection bias might have produced a certain ceiling effect on parent-clinician agreement. Although the agreement measures were not identical, participants in our perspective taking study showed higher agreement scores and less variation ($M = 54.78$; $SD = .09$) compared to participants in a normative sample ($M = 25.29$; $SD = 9$; Marangoni et al., 1995). Perhaps conducting the study in another centre, where general motivation is lower, would yield a greater variety of scores and allow for the detection of a significant experimental effect. In the first study, physician compassionate care and accuracy on the BDI-SF were found to significantly differ across different cancer centres. The selection of patients by physicians may also have been biased. For instance, the physicians could have been inclined to choose patients according to level of distress and quality of relationship, both of which were found to be associated with physician accuracy (Lelorain et al. 2014).

A third important limitation is the over-representation of women in our samples. Male and female professionals showed a close to significant difference on detection of distress in our

first study. Nonetheless, research has not identified major gender differences in clinical empathy (Hojat et al., 2002; Hojat et al., 2001) or emotion identification (Ickes & Hodges, 2013; Marangoni et al., 1995).

A fourth limitation may be perceived in the use of agreement scores as measures of clinician accuracy. One may wonder whether patients' and parents' reports of personal distress through questionnaires and the standard stimulus paradigm are as valid as formal psychological assessment procedures. This is a legitimate concern, since structured interview methods like the Structured Clinical Interview for DSM Disorders (SCID) should theoretically serve as the gold standard. However, even the most rigorous assessment procedures rely on patient response and are therefore imperfect. Keller et al. (2004) examined clinician ability to recognize distress using two gold standards: DSM-IV diagnoses and patient-reported distress on the Hospital Anxiety and Depression Scale. The two methods yielded strikingly similar values of sensitivity and specificity. Such a finding supports the validity of brief questionnaires as appropriate tools for evaluating patient-clinician agreement on patient distress. In addition, the use of simple self-report measures allows for direct comparisons of patient/parent and clinician scores on specific symptoms. Such precision would be lost in a study comparing psychiatric diagnoses to clinicians' ratings of global distress. Finally, the scope of structured interviews is limited, as it dismisses non-pathological distress. Using brief questionnaires in our first study allowed us to consider subclinical levels of distress and minimize the number of false negatives. This corroborates the purpose of screening, which serves as a preliminary step to formal psychological evaluation.

Despite having notable strengths, the second study's methodology also has a few limitations. To begin, the sample is more representative of nurses than other types of

professionals. No significant association between profession and parent-clinician agreement was detected. However, research does suggest that nurses tend to show better recognition of distress than physicians (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Fukui, Ogawa, Ohtsuka, & Fukui, 2009; Keller et al., 2004; Mitchell et al., 2011; Okuyama et al., 2011; Söllner et al., 2001; Trask et al., 2002; Werner et al., 2011). This could have been apparent in a sample with equal numbers of nurses and physicians. A second methodological limitation is that the effectiveness of the imagine-self perspective may have been reduced by the instruction to infer parent thoughts and feelings on the standardized recording form. This instruction is essentially similar to the “imagine-other” instruction, which asks participants to imagine the parents’ feelings and personal experiences. Thus, it may have incited some participants in the imagine-self group to ignore the initial perspective taking instructions. A third methodological limitation is that the effectiveness scales used in this study have not been formally validated. This includes the imagine-self scale used in the correlational analyses. The corresponding results should therefore be considered as preliminary data. Lastly, a few aspects limit the ecological validity of the stimulus video. Since the final video is a replication of interviews conducted with the actual parents, the expression of emotions is not identical to that of the original version. However, as explained in the study’s discussion, any differences between the two versions would likely have a conservative effect on parent-clinician agreement. Lastly, the parents who participated in the creation of the stimulus video did not have particularly high levels of distress and were judged to have relatively good coping strategies. Thus, they do not accurately portray the whole array of distress levels experienced by parents of children with cancer.

Strengths and Future Directions

The present thesis project contributes to scientific literature through the innovative integration of social psychological theory and methodology in psycho-oncology research. It also sheds light on populations which, most likely due to their small numbers and limited accessibility, are rarely studied in this area of research. Another important strength is the precision and psychometric quality of the methods used to analyze patient-physician and parent-clinician agreement. In the first study, we were careful to avoid common errors in the selection of global indices of patient-physician agreement. Moreover, performing the analyses at a symptom level allowed us to make more detailed and nuanced interpretations. In the second study, we used a validated measure of parent-clinician agreement proposed by Marangoni et al. (1995); (Ickes, 2001; Ickes & Hodges, 2013; Schmid Mast & Ickes, 2007; Zaki, Bolger, & Ochsner, 2008). The psychometric value of this method stands in contrast to other continuous measures of agreement such as absolute difference of scores or inferences by multiple choice, which fail to meet the criteria for a theoretically grounded measure of empathic accuracy (Ickes, 1993). In addition, the quasi-experimental nature of the second study's design provides solid evidence of the emotional outcomes associated with perspective taking. Although no group differences were found on ability to detect distress, this work provides important indications for the design of future experiments.

We have identified a few interesting directions for future research on detection of distress and perspective taking. Replications of the perspective taking study should include larger samples of clinicians randomly selected across multiple centres to ensure a more accurate representation of hematology-oncology professionals. More elaborate interventions should be designed to increase their level of efficacy. Indeed, future research ought to examine a variety

of methods. Categorically new ways of influencing clinicians' perspective taking could be tested. Similar to other-oriented perspective taking, research amongst oncology professionals has suggested that mindfulness may increase awareness of emotions in oneself and in others, while preventing professional burnout (Birnie, Speca, & Carlson, 2010; Lamothe, Rondeau, Malboeuf-Hurtubise, Duval, & Sultan, 2016). It may therefore prove to be a valuable skill for accurate detection of distress. Eventually, studies could compare different teaching strategies (e.g. lecture vs. role play; one-time event vs. booster sessions) in various clinical situations (e.g. individual vs. group consultations; confrontational vs. harmonious interactions). Differences in clinicians' personal characteristics may also call for added coaching strategies. For instance, professionals experiencing burnout may lack the empathic concern and motivation needed to apply perspective taking strategies. Once a better understanding of perspective taking has been achieved, a new component could be added to existing empathy training programmes. The effect on clinicians' ability to detect distress could then be tested in larger clinical trials.

Conclusion

The present thesis project contributes to a new line of research examining perspective taking and other empathic skills as strategies for improving detection of distress experienced by adults with cancer and their family members. It also lends support to previous findings on clinician ability to detect distress and the emotional outcomes of perspective taking. Our findings suggest that empathic skills such as imagine-other perspective taking may be associated with more accurate detection of distress by clinicians and reduce clinician distress. Nonetheless, more research is needed to experimentally investigate the effect of perspective taking type on clinician accuracy. This research will most likely contribute to the development of evidence-based training programmes aimed at improving health care professionals' empathic skills, as

well as protecting their psychological well-being. With its interdisciplinary approach, this work broadens the potential for initial and continuing education in patient-centred health care.

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Appendix A

Beck Depression Inventory – Short Form (Patient Version)

Etat émotionnel : questionnaire BDI-SF

Pour chaque série, lisez les quatre propositions, puis choisissez celle qui décrit le mieux votre état actuel. Entourez le numéro qui correspond à la proposition choisie. Si, dans une série, plusieurs propositions paraissent convenir, entourez les numéros correspondants.

- A. Je ne me sens pas triste. 0
Je me sens cafardeux(euse) ou triste. 1
Je me sens tout le temps cafardeux(euse) ou triste, et je n'arrive pas à en sortir. 2
Je suis si triste et si malheureux(euse) que je ne peux pas le supporter. 3
- B. Je ne suis pas particulièrement découragé(e) ni pessimiste au sujet de l'avenir. 0
J'ai un sentiment de découragement au sujet de l'avenir. 1
Pour mon avenir, je n'ai aucun motif d'espérer. 2
Je sens qu'il n'y a aucun espoir pour mon avenir, et que la situation ne peut s'améliorer. 3
- C. Je n'ai aucun sentiment d'échec de ma vie. 0
J'ai l'impression que j'ai échoué dans ma vie plus que la plupart des gens. 1
Quand je regarde ma vie passée, tout ce que j'y découvre n'est qu'échecs. 2
J'ai un sentiment d'échec complet dans toute ma vie personnelle (dans mes relations avec mes parents, mon mari, ma femme, mes enfants). 3
- D. Je ne me sens pas particulièrement insatisfait(e). 0
Je ne sais pas profiter agréablement des circonstances. 1
Je ne tire plus aucune satisfaction de quoi que ce soit. 2
Je suis mécontent(e) de tout. 3
- E. Je ne me sens pas coupable. 0
Je me sens mauvais(e) ou indigne une bonne partie du temps. 1
Je me sens coupable. 2
Je me juge très mauvais(e) et j'ai l'impression que je ne vauds rien. 3
- F. Je ne suis pas déçu(e) par moi-même. 0
Je suis déçu(e) par moi-même. 1
Je me dégoûte moi-même. 2
Je me hais. 3
- G. Je ne pense pas à me faire du mal. 0
Je pense que la mort me libérerait. 1
J'ai des plans précis pour me suicider. 2
Si je le pouvais, je me tuerais. 3
- H. Je n'ai pas le sentiment d'être plus laid(e) qu'avant. 0
J'ai peur de paraître vieux(vieille) ou disgracieux(se). 1
J'ai l'impression qu'il y a un changement permanent dans mon apparence physique qui me fait paraître disgracieux(se). 2
J'ai l'impression d'être laid(e) et repoussant(e). 3

Distress Thermometer (Patient Version)

Votre état psychologique

L'échelle ci-dessous représente un moyen d'apprécier votre état psychologique. Mettez, svp, une croix sur la ligne à l'endroit qui correspond le mieux à votre état psychologique de la dernière semaine.

Détresse très importante



Pas de détresse

parce que chaque personne est différente.

- 7._____ Quand j'interroge mes patients sur leurs antécédents ou leur santé physique, j'essaie de ne pas prêter attention à leurs émotions.
- 8._____ Être attentif au vécu de mes patients n'influence pas les résultats des traitements.
- 9._____ Quand je soigne mes patients, j'essaie de me mettre à leur place.
- 10._____ Mes patients accordent de l'importance au fait que je comprenne leurs sentiments, ce qui est thérapeutique en soi.
- 11._____ Les maladies des patients ne peuvent être guéries que par traitement médical ou chirurgical ; ainsi, les liens émotionnels avec mes patients n'ont pas d'influence significative sur les résultats médicaux ou chirurgicaux.
- 12._____ Interroger les patients sur ce qui se passe dans leurs vies personnelles n'est pas utile pour comprendre les plaintes liées à leur état physique.
- 13._____ J'essaie de comprendre ce qui se passe dans l'esprit de mes patients en prêtant de l'attention aux signes non verbaux et au langage corporel.
- 14._____ Je pense que l'émotion n'a pas sa place dans le traitement de la maladie physique.
- 15._____ L'empathie est une compétence thérapeutique sans laquelle le succès du traitement est limité.
- 16._____ Ma compréhension de l'état émotionnel de mes patients tout comme celui de leurs familles est une composante importante de la relation.
- 17._____ J'essaie de penser comme mes patients pour leur offrir de meilleurs soins.
- 18._____ Je ne me laisse pas influencer lorsqu'il y a de fortes relations personnelles entre mes patients et les membres de leurs familles.
- 19._____ Je n'ai pas de plaisir à lire de la littérature non médicale ou à m'intéresser aux arts.
- 20._____ Je crois que l'empathie est un facteur thérapeutique important dans le traitement médical ou chirurgical.

Quality of Patient-Physician Relationship

Quelle est la qualité de la relation que vous entretenez avec ce patient? (svp, entourez le chiffre adéquat)

Relation très difficile										Relation très aisée
	1	2	3	4	5	6	7	8	9	

Beck Depression Inventory – Short Form & Distress Thermometer (Physician Version)

Questionnaire BDI-SF

Ce questionnaire porte sur l'état émotionnel du patient actuellement. Pour chaque question, veuillez, svp, entourer le chiffre correspondant à la réponse que le patient a dû donner. A votre avis, qu'a répondu le (la) patient(e)?

- A. Je ne me sens pas triste. 0
Je me sens cafardeux(euse) ou triste. 1
Je me sens tout le temps cafardeux(euse) ou triste, et je n'arrive pas à en sortir. 2
Je suis si triste et si malheureux(euse) que je ne peux pas le supporter. 3
- B. Je ne suis pas particulièrement découragé(e) ni pessimiste au sujet de l'avenir. 0
J'ai un sentiment de découragement au sujet de l'avenir. 1
Pour mon avenir, je n'ai aucun motif d'espérer. 2
Je sens qu'il n'y a aucun espoir pour mon avenir, et que la situation ne peut s'améliorer. 3
- C. Je n'ai aucun sentiment d'échec de ma vie. 0
J'ai l'impression que j'ai échoué dans ma vie plus que la plupart des gens. 1
Quand je regarde ma vie passée, tout ce que j'y découvre n'est qu'échecs. 2
J'ai un sentiment d'échec complet dans toute ma vie personnelle (dans mes relations avec mes parents, mon mari, ma femme, mes enfants). 3
- D. Je ne me sens pas particulièrement insatisfait(e). 0
Je ne sais pas profiter agréablement des circonstances. 1
Je ne tire plus aucune satisfaction de quoi que ce soit. 2
Je suis mécontent(e) de tout. 3
- E. Je ne me sens pas coupable. 0
Je me sens mauvais(e) ou indigne une bonne partie du temps. 1
Je me sens coupable. 2
Je me juge très mauvais(e) et j'ai l'impression que je ne vauds rien. 3
- F. Je ne suis pas déçu(e) par moi-même. 0
Je suis déçu(e) par moi-même. 1
Je me dégoûte moi-même. 2
Je me hais. 3
- G. Je ne pense pas à me faire du mal. 0
Je pense que la mort me libérerait. 1
J'ai des plans précis pour me suicider. 2
Si je pouvais, je me tuerais. 3
- H. Je n'ai pas le sentiment d'être plus laid(e) qu'avant. 0
J'ai peur de paraître vieux(vieille) ou disgracieux(se). 1
J'ai l'impression qu'il y a un changement permanent dans mon apparence physique qui me fait paraître disgracieux(se). 2
J'ai l'impression d'être laid(e) et repoussant(e). 3

Son état psychologique

L'échelle à droite représente un moyen d'apprécier l'état psychologique du patient. Il (elle) devait mettre une croix sur la ligne à l'endroit qui correspondait le mieux à son état psychologique de la dernière semaine. A votre avis, où le patient a-t-il mis la croix?

Détresse très importante

Pas de détresse

Berkeley Expressivity Questionnaire

Pour chaque énoncé ci-dessous, veuillez indiquer si vous êtes en accord ou en désaccord. Inscrivez devant chaque item le chiffre qui convient, en utilisant l'échelle suivante :

1	2	3	4	5	6	7
Fortement en désaccord			Neutre			Fortement en accord

- ____ 1. À chaque fois que je ressens des émotions positives, les gens peuvent facilement voir exactement ce que je ressens.
- ____ 2. Je pleure parfois en écoutant des films tristes.
- ____ 3. Les gens ignorant souvent ce que je ressens.
- ____ 4. Je ris à voix haute quand quelqu'un me raconte une blague que je trouve drôle.
- ____ 5. C'est difficile pour moi de cacher ma peur.
- ____ 6. Quand je suis heureux(se), ça se voit.
- ____ 7. Mon corps réagit très fortement aux situations émotionnelles.
- ____ 8. J'ai appris que c'est mieux de refouler ma colère que de la montrer.
- ____ 9. Peu importe à quel point je suis nerveux(se) ou fâché(e), j'ai tendance à garder un extérieur calme.
- ____ 10. Je suis une personne qui exprime ses émotions.
- ____ 11. J'ai des émotions fortes.
- ____ 12. Je suis parfois incapable de cacher mes sentiments, même si j'aimerais pouvoir le faire.
- ____ 13. Lorsque je ressens des émotions négatives, les gens peuvent facilement voir exactement ce que je ressens.
- ____ 14. Il y a eu des moments où je n'arrivais pas à arrêter de pleurer, même si j'essayais.
- ____ 15. Je ressens mes émotions très fortement.
- ____ 16. On peut lire sur mon visage tout ce que je ressens.

Thought and Feeling Recording Form (Parent Version)

Date _____

N. identification _____

Dans quelques minutes, vous réécoutez la deuxième partie de votre entrevue. Veuillez employer la grille ci-dessous pour rapporter TOUTES les pensées et les sentiments dont vous vous rappelez avoir vécus **durant l'entrevue**. Ne pas rapporter les pensées et les sentiments qui surviennent seulement à la réécoute.

Là où vous vous rappelez avoir pensé ou senti quelque chose, veuillez mettre la vidéo sur pause et rapporter le temps d'arrêt dans la grille. Ensuite, indiquez s'il s'agit d'une pensée ou d'un sentiment en cochant la case appropriée. En une phrase, résumez le contenu de la pensée ou du sentiment dans l'espace fournie. SVP, faites ceci avec autant de précision et d'honnêteté possible. Si vous viviez une pensée et un sentiment en même temps, choisissez l'un des deux en priorisant celui qui vous semble le plus important. Finalement, indiquez si le contenu est positif (+), neutre (0) ou négatif (-) en encerclant le symbole approprié. Notez qu'après cette activité, vous aurez la chance de supprimer tout contenu que vous préférez garder privé.

Temps	Pensée ou sentiment	+, 0, -
	<input type="checkbox"/> Je pensais à: OU <input type="checkbox"/> Je sentais:	+ 0 -
	<input type="checkbox"/> Je pensais à: OU <input type="checkbox"/> Je sentais:	+ 0 -
	<input type="checkbox"/> Je pensais à: OU <input type="checkbox"/> Je sentais: ...	+ 0 -

This form is based on the original developed by Marangoni et al. (1995).

Thought and Feeling Inference Form (Clinician Version)

Date _____

N. identification _____

Vous vous apprêtez à visionner la deuxième partie de la vidéo. À plusieurs reprises, l'assistant(e) de recherche arrêtera la vidéo. Vous devrez alors inférer soit la pensée ou le sentiment du parent.

Veillez d'abord indiquer s'il s'agit d'une pensée ou d'un sentiment, en cochant la case appropriée. Ensuite, en une phrase, résumez le contenu de la pensée ou du sentiment dans l'espace fournie. SVP, faites ceci avec autant de précision possible.

Temps	Pensée ou sentiment
1	<input type="checkbox"/> Le parent pensait à: OU <input type="checkbox"/> Le parent sentait:
2	<input type="checkbox"/> Le parent pensait à: OU <input type="checkbox"/> Le parent sentait:
3	<input type="checkbox"/> Le parent pensait à: OU <input type="checkbox"/> Le parent sentait:
4	<input type="checkbox"/> Le parent pensait à: OU <input type="checkbox"/> Le parent sentait: ...

This form is based on the original developed by Marangoni et al. (1995).

Intervention Effectiveness Scales

Lors du visionnement, ...

...à quel point étiez-vous concentré sur les sentiments que vous auriez si vous viviez les expériences que les parents décrivaient en entrevue?

Pas du tout									Très concentré
concentré sur cela									sur cela
1	2	3	4	5	6	7	8	9	

...à quel point étiez-vous concentré sur les sentiments des parents?

Pas du tout									Très concentré
concentré sur cela									sur cela
1	2	3	4	5	6	7	8	9	

Personal Habits

Lorsque vous tentez de comprendre les émotions d'un parent, laquelle des deux stratégies suivantes employez-vous **le plus fréquemment**? Veuillez encercler la lettre correspondant à votre réponse.

- Vous essayez d'imaginer comment le parent se sent par rapport à sa situation et comment celle-ci affecte sa vie en observant ses réactions.
- Vous essayez d'imaginer comment vous vous sentiriez si vous viviez la même chose que le parent et comment ceci affecterait votre vie.

Quelle stratégie avez-vous employée le plus fréquemment aujourd'hui? Indiquez a ou b : _____

Emotional Response Scale

Veillez indiquer, en encerclant un chiffre, avec quel degré d'intensité vous avez vécu chacune de ces réactions émotionnelles pendant que vous visionniez la vidéo. Ne vous inquiétez pas si vous n'avez pas senti plusieurs de ces émotions; seulement quelques-unes peuvent s'appliquer. Assurez-vous d'encercler une réponse pour chaque émotion.

	Pas du tout		Modérément			Extrêmement	
1. alarmé(e)	1	2	3	4	5	6	7
2. chagriné(e)	1	2	3	4	5	6	7
3. sympathique	1	2	3	4	5	6	7
4. attentif(ve)	1	2	3	4	5	6	7
5. avoir le cœur doux	1	2	3	4	5	6	7
6. troublé(e)	1	2	3	4	5	6	7
7. chaleureux(se)	1	2	3	4	5	6	7
8. préoccupé(e)	1	2	3	4	5	6	7
9. affligé(e)	1	2	3	4	5	6	7
10. déprimé(e)	1	2	3	4	5	6	7
11. intrigué(e)	1	2	3	4	5	6	7
12. compatissant(e)	1	2	3	4	5	6	7
13. fâché(e)	1	2	3	4	5	6	7
14. bouleversé(e)	1	2	3	4	5	6	7
15. tendre	1	2	3	4	5	6	7
16. inquiet(e)	1	2	3	4	5	6	7

17. ému(e)	1	2	3	4	5	6	7
18. déconcerté(e)	1	2	3	4	5	6	7
19. se sentir faible	1	2	3	4	5	6	7
20. perturbé(e)	1	2	3	4	5	6	7
21. avoir le cœur gros	1	2	3	4	5	6	7
22. chagrin(e)	1	2	3	4	5	6	7
23. dérangé(e)	1	2	3	4	5	6	7
24. aimable	1	2	3	4	5	6	7
25. triste	1	2	3	4	5	6	7
26. touché(e)	1	2	3	4	5	6	7

Interpersonal Reactivity Index

Indiquez en utilisant les indications qui figurent ci-dessous à quel point vous êtes en **Désaccord ou en Accord** avec chacune des affirmations qui suivent. Ne donnez qu'une réponse pour chaque proposition, puis **reportez dans la case de droite le chiffre correspondant**. Vous n'utiliserez le milieu de l'échelle que s'il vous est tout à fait impossible de porter un jugement sur votre manière de réagir.

Désaccord complet	Désaccord relatif	Ni accord, ni désaccord	Accord relatif	Accord complet
1	2	3	4	5

1) Assez régulièrement, je rêve et fantasme à propos de choses qui pourraient m'arriver.	1) __
2) J'ai souvent des sentiments de tendresse, de compassion pour les personnes moins favorisées que moi.	2) __
3) Je trouve parfois difficile de voir les choses du point de vue de l'autre.	3) __
4) Il m'arrive de ne pas me sentir sincèrement désolé(e) pour les autres lorsqu'ils ont des problèmes.	4) __
5) Je deviens vraiment absorbé(e) par les sentiments des personnages d'un roman.	5) __
6) Dans les situations d'urgence, je me sens inquiet(e) et mal à l'aise.	6) __
7) Lorsque je regarde un film ou une pièce de théâtre, je suis généralement objectif(ve), et il est rare que je sois complètement pris(e) dedans.	7) __
8) En cas de désaccord, j'essaie de voir le point de vue de chacun avant de prendre une décision.	8) __
9) Lorsque je vois une personne se faire exploiter, j'éprouve un certain sentiment de protection envers elle/à son égard.	9) __

10) Je me sens parfois désarmé(e) lorsque je me trouve au cœur d'une situation très émotionnelle.	10) __
11) Parfois, j'essaie de mieux comprendre mes ami(e)s en imaginant comment les choses se présentent de leur point de vue.	11) __
12) C'est assez rare que je sois fortement absorbé(e) par un bon livre ou un bon film.	12) __
13) Quand je vois qu'on fait du mal à quelqu'un, j'ai tendance à garder mon calme.	13) __
14) D'habitude, les malheurs des autres ne m'affectent pas vraiment.	14) __
15) Si je suis sûr(e) d'avoir raison sur un point, je ne perds pas tellement de temps à écouter les arguments des autres.	15) __
16) Après avoir vu une pièce de théâtre ou un film, il m'est arrivé de me sentir comme si j'étais un des personnages.	16) __
17) Me trouver dans une situation de tension émotionnelle me fait peur.	17) __
18) Il m'arrive de ne pas éprouver de pitié pour les personnes que je vois être traitées injustement.	18) __
19) En général, je suis plutôt efficace dans les situations d'urgence.	19) __
20) Je suis souvent assez touché(e) par les événements que je vois se produire.	20) __
21) Je crois qu'il y a deux côtés à toute question et j'essaie de les regarder tous les deux.	21) __
22) J'aurais tendance à me décrire comme une personne au cœur tendre/sentimentale.	22) __
23) Lorsque je regarde un bon film, je peux très facilement me mettre à la place du personnage principal.	23) __
24) J'ai tendance à perdre le contrôle de moi-même dans les situations d'urgence.	24) __

25) Quand j'en veux à quelqu'un, j'essaie habituellement de me mettre 'dans sa peau' pendant un moment.	25) __
26) Lorsque je suis en train de lire une histoire intéressante, j'imagine ce que je ressentirais si les événements de l'histoire m'arrivaient.	26) __
27) Je pers mes moyens quand je vois quelqu'un qui a gravement besoin d'aide dans une situation d'urgence.	27) __
28) Avant de critiquer quelqu'un, j'essaie d'imaginer comment je me sentirais si j'étais à sa place.	28) __

Appendix B

Semi-Structured Interview

Aujourd'hui on se rencontre pour parler de votre expérience avec le cancer pédiatrique et des impacts émotionnels reliés. D'abord, je vais vous demander des questions portant sur votre histoire. Ensuite, on abordera les aspects émotionnels de votre cheminement. S'il y a des bouts de l'entrevue que vous souhaitez garder confidentiels, nous pouvons les supprimer sans problème. Ça vous va?

Avez-vous des questions avant qu'on commence?

1ère partie

1. Comment avez-vous appris que (nom de l'enfant) avait le cancer?
2. Quelle était votre première réaction?
3. Comment (nom de l'enfant) l'a-t-il(elle) appris? Quelle était sa réaction?
4. Voulez-vous brièvement me raconter comment la santé de (nom de l'enfant) a progressé par la suite?
5. Aujourd'hui, comment va (nom de l'enfant)?

2ième partie

1. Depuis le diagnostic, qu'est-ce qui a été le plus difficile pour vous, personnellement? Pour la famille?
2. Malgré les moments difficiles, il doit en avoir des plus heureux... Voulez-vous me donner un exemple ou deux?
3. Comment ça va pour vous ces-jours-ci?
 - a. Qu'est-ce qui est plus difficile?
4. Quels sont des impacts (positifs ou négatifs) du cancer sur votre vie actuelle?

Conclusion (varie en fonction du déroulement de l'entrevue). p.ex. « Pour terminer, j'aimerais savoir comment vous vous êtes sentie durant notre rencontre? (...) Le temps fil, il va donc falloir s'arrêter bientôt. Je comprends que ça n'a pas toujours été facile pour vous au niveau de ... En même temps, je sens que... Merci beaucoup d'avoir partagé votre histoire. Je sais que ça fait remonter toutes sortes d'émotions. » Suggérer des ressources au besoin.