The Role of the Physician in Secondary Prevention of Melanoma through Skin Self-Examination

during Melanoma Follow-up Care

Zofia Czajkowska, PhD Cand.

Department of Educational and Counselling Psychology

McGill University, Montréal

July, 2018

A thesis submitted to McGill University in partial fulfillment of the requirements of the

degree of doctor of philosophy in Counselling Psychology

Contents

Abstract

Introduction (Chapter 1) presents an overview of the research literature on melanoma and its prevention. Melanoma is the fastest growing and most lethal cancer of the skin (Trask et al., 2001). Its incidence in North America continues to rise annually posing a threat to an increasing number of individuals (American Cancer Society, 2018a; Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017). Given this increase it is imperative to implement effective primary and secondary preventative strategies, especially for those at highest risk. Clinical care guidelines recommend Skin Self-Examination (SSE) as an essential part of the lifetime follow-up care for melanoma survivors, who are at high risk for recurrence and new primary tumours (Coit et al., 2009; National Comprehensive Cancer Network, 2018). Patient predictors of SSE include age, gender, income, educational attainment, patient self-efficacy, as well as patient education regarding SSE, among others (Carli et al., 2003; Coups, Manne, Stapleton, Tatum, & Goydos, 2016; Kasparian et al., 2012; Kasparian et al., 2010; Manne & Lessin, 2006; McLoone, Menzies, Meiser, Mann, & Kasparian, 2013; K. A. Miller et al., 2015; Robinson, Fisher, & Turrisi, 2002; Robinson, Rigel, & Amonette, 1998). Less is known about the role of the physician support for uptake and maintenance of SSE practice (Aitken et al., 2004; Manne et al., 2004; Manne & Lessin, 2006; Rat et al., 2014). Consequently, the present dissertation reports on research examining the role of the above-mentioned variables for SSE behaviour.

First, Health Care Climate Questionnaire (HCCQ), a measure of patient perceptions of general physician support of patient autonomy, was translated from the original English to French (Williams, Freedman, & Deci, 1998; Williams, Grow, Freedman, Ryan, & Deci, 1996). Then, validation analyses of the 6-item version of the HCCQ were conducted. The results (reported in Chapter 2) indicate that the scale is valid for use with melanoma survivors in both languages.

Second, an intervention educating participants on early signs of melanoma and how to detect it via SSE was presented in Chapter 3. Participants' self-efficacy for SSE increased by 23% following the intervention and the improvements were retained at a three- and twelve-month follow-up. Analyses revealed that perceived physician support of SSE positively corresponded to the level of patient self-efficacy with higher patient-reported physician support being related to higher self-efficacy.

Third, the relationship between the sociodemographic predictors of SSE (age, gender, income and education), physician support of SSE, self-efficacy and the practice of skin self-exams was further elucidated in Chapter 4. The level of SSE-specific self-efficacy was found to partially mediate the association between physician support of SSE and SSE behaviour after accounting for the only significant sociodemographic correlate of SSE in the current sample, i.e., education.

Overall, the findings presented in the current dissertation suggest that educating patients about SSE and encouraging them to engage in it may have an impact on their confidence in the ability to perform effective self-exams. Moreover, physicians treating melanoma survivors may have a very important role to play in secondary prevention of this skin malignancy, not only through clinical exams but also through providing SSE-specific support to their patients, as per clinical care guidelines. The current research indicates that such support may not only increase patients' self-efficacy for this practice but also improve the practice of skin self-exams. The implications for research and practice are discussed in Chapter 5.

Keywords: melanoma, skin self-examination, secondary prevention, physician support, self-efficacy, validation

Résumé

Introduction (Chapitre 1) présente un survol de la littérature concernant le mélanome et sa prévention. Le mélanome est le cancer de la peau le plus létal et celui dont l'incidence a la croissance la plus rapide (Trask et al., 2001). Son incidence en Amérique du Nord continue d'augmenter annuellement et pose un risque à un nombre croissant d'individus (American Cancer Society, 2018a; Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017). Du a cette croissance il est impératif d'implémenter des stratégies de prévention efficaces. Les directives cliniques recommandent L'Auto-examen de la peau (AEP) comme un élément essentiel du calendrier de suivi des survivants du mélanome qui sont à haut risque de récurrence et de nouvelles tumeurs (Coit et al., 2009; National Comprehensive Cancer Network, 2018). Les prédicteurs de l'AEP incluent entre autres, l'âge, le genre, le salaire, l'accomplissement éducationnel, l'auto-efficacité du patient et aussi l'éducation du patient envers l'AEP (Carli et al., 2003; Coups et al., 2016; Kasparian et al., 2012; Kasparian et al., 2010; Manne & Lessin, 2006; McLoone et al., 2013; K. A. Miller et al., 2015; Robinson et al., 2002; Robinson et al., 1998).

Peu de choses sont connues au sujet du rôle du support du médecin de la pratique de l'AEP (Aitken et al., 2004; Manne et al., 2004; Manne & Lessin, 2006; Rat et al., 2014). Conséquemment, la présente dissertation se rapporte à l'analyse et l'élucidation de la relation entre les variables mentionnées ci-haut dans la prédiction du comportement envers l'AEP.

Premièrement, une traduction du Health Care Climate Questionnaire (HCCQ), une mesure de la perception du patient du support des médecins envers l'autonomie du patient, provenant de l'anglais original vers le français a été achevé (Williams, Freedman, et al., 1998; Williams et al., 1996). Par la suite, une analyse de validation de la version brève du HCCQ (6 items) a été effectué.

Les résultats (rapporté au Chapitre 2) indiquent que cette mesure est valide et utile dans les deux langages.

Deuxièmement, les résultats d'une intervention visant à éduquer les participants sur les signes précoces du mélanome et comment les détecter avec l'AEP ont été présenté au Chapitre 3. L'auto-efficacité des participants a augmenté de 23% suivant l'intervention et les améliorations ont été retenues lors des suivis de trois et douze mois. Des analyses ont révélé que la perception du support du médecins envers l'AEP correspond de façon positive envers le niveau d'auto-efficacité lorsqu'un niveau élevé de support du médecin envers l'AEP a été rapporté.

Troisièmement, la relation entre les prédicteurs socio-démographiques de l'AEP (âge, genre, salaire et éducation), le support du médecin envers l'AEP, l'auto-efficacité et la pratique de l'AEP a été élucidé de façon plus approfondie au Chapitre 4. La médiation entre le support du médecin envers l'AEP et le comportement envers l'AEP par l'auto-efficacité spécifique à l'AEP a été démontré après avoir corrigé pour le seul facteur socio-démographique qui corrèle de façon significative dans le présent échantillon, i.e., l'éducation.

Globalement, les résultats de la présente thèse suggèrent que l'éducation des patients envers l'AEP et de les encourager à s'y engager ont un impact sur leur confiance dans leurs habiletés à pratiquer un AEP. De plus, les médecins traitants les survivants du mélanome on possiblement un rôle très important à jouer dans la prévention secondaire de ce cancer, non seulement avec des examens cliniques (suivi standard pour le mélanome) mais aussi en fournissant un support spécifique à l'AEP à leurs patients, conformément aux directives cliniques. La présente recherche indique qu'un tel support augmente l'auto-efficacité de cette pratique et améliore l'AEP en soi. Les implications pour la recherche et pour la pratique clinique sont discutées au Chapitre 5.

Les mots clés: le mélanome, L'Auto-examen de la peau, la prévention secondaire, le support de médecin, l'auto-efficacité, validation

Acknowledgements

First, I would like to thank all research participants who have generously contributed their time and efforts to making this work possible. Similarly, I truly appreciate the hard work put in by all the volunteers, students and research coordinators of the Health Psychology Research Group over the years. Without this "background" work, the scaffolding necessary to build a solid research project would not have been possible. Thank you!

Further, I would like to thank my dissertation committee members: Dr. Nathan Hall (and his student Hui Wang) as well as Maida Sewitch. They stood by me for years providing invaluable feedback on all my work and being patient with all my work interruptions, while I was growing my family. You did not only help me move swiftly through different steps of the PhD program and publish our research results but you also made me a better writer. I truly appreciate that. That is a gift I will carry forward and use for the rest of my life. Thank you.

Next, I would like to offer my thanks and gratitude to my research supervisor, Dr. Annett Körner, who has supported me and my research throughout my graduate studies. If it wasn't for Annett, I would not pursue a PhD degree and I am eternally grateful to her for bringing me onboard of her research. I was her first student and I have cherished that role over the years. She had assisted me with her knowledge and expertise well – that is what is expected of a good supervisor. What is more, Annett went above and beyond the usual supervisory role by providing me with multiple opportunities to learn and grow throughout the process, including work-opportunities, conferences, and networking. Throughout our working relationship Annett has been very generous, flexible and patient, and I appreciate those qualities very much – they should not be taken for granted. Moreover, she has made a seemingly illusory work-life balance possible for me,

which is something I appreciate the most. I could not have found a more supportive supervisor if I tried. Thank you.

I would also like to add special thanks to my life partner, Michel Vienneau, who has supported me on this long and sometime arduous journey along with its ups and downs. He has been there for me through it all, a bottomless well of patience, and I cannot imagine completing my degree without him. He knew I could do it and never doubted my ability to finish. He has always been there for me. Thank you, love.

Lastly, I would like to thank my parents, Alicja and Piotr, for instilling in me the sense of confidence necessary to accomplish all the steps leading up to a PhD. My parents raised me to believe that I am smart and capable and because of them I have never had a doubt that I can become "a doctor". Despite many frustrations along the way, typical of a doctoral student experience, I had never had a moment of doubt wondering if I can succeed. That is a great gift many parents struggle to bestow on their children yet so necessary to accomplish anything that requires dedication and sustained effort for years. I hope I will be able to do the same for my wonderful children, Adam and Alex. Thank you for your love and support, instilling in me the value of hard work and teaching me to never give up. I am forever grateful to you. Thank you.

Contribution of Authors

Each of the three manuscripts included in this dissertation represent original research data, which was obtained from a larger-scale research project conducted by Dr. Annett Körner's Health Psychology Research Group (HPRG). I am the first author on all three papers since I completed the literature reviews, selected the measures, conceived of the original research questions for each paper (with my supervisor's guidance), analyzed and interpreted the data, and composed the entire dissertation. The first manuscript (Chapter 2) is co-authored by Dr. Hui Wang (PhD Candidate at the time), Dr. Nathan Hall, Dr. Maida Sewitch as well as Dr. Annett Körner. The second paper (Chapter 3) is co-authored by Dr. Nathan Hall, Dr. Maida Sewitch, Dr. Beatrice Wang and Dr. Annett Körner. The last (Chapter 4) is co-authored by Dr. Nathan Hall, Dr. Maida Sewitch as well as Dr. Annett Körner.

My doctoral research supervisor, Dr. Annett Körner, is responsible for conceiving and conducting the large-scale study examining the secondary prevention of melanoma (Körner et al., 2013). She devised the procedures and methods of data collection as well as secured funding for the project (see below). She assisted in the conceptualization of the dissertation, in the derivation of research questions, supervised the selection of scales, data analysis, and interpretations, and edited all 3 manuscripts as well as related conference presentations. Dr. Nathan Hall, a member of the dissertation committee, is co-author on all three manuscripts, as he assisted in the statistical decision-making for all three papers, in addition to providing editorial comments. His student, Hui Wang, assisted with the confirmatory factor analyses presented in manuscript 1 (Chapter 2). Dr. Maida Sewitch, a second committee member who is co-author on all three manuscripts, provided valuable editorial comments for all three manuscripts and the dissertation as a whole. Dr. Beatrice Wang, a co-author on the second manuscript (Chapter 3),

List of abbreviations

α Alpha

ANOVA Analysis of Variance

β Beta

CFA Confirmatory Factor Analysis

CFI Comparative Fit Index

CI Confidence Interval

DT Distress Thermometer

EFA Exploratory Factor Analyses

HCCQ Health Care Climate Questionnaire

ICC Intraclass correlation coefficient

M Mean

NCCN National Comprehensive Cancer Network

PHQ-4 Patient Health Questionnaire-4

SCI Skin Cancer Index

SD Standard Deviation

SSE Skin self-examination

SPSS Statistical Package for the Social Sciences

SRMR Standardized Root Mean Residual

RA Research Assistant

RMSEA Root Mean Square Error of Approximation

TLI Tucker–Lewis Index

Chapter 1

Introduction

Background on melanoma

Definition and aetiology

Malignant cutaneous melanoma (from here on referred to as "melanoma") is the fastest growing cancerous tumour of the skin. It originates in the cells called melanocytes found in the deeper layer of the skin, the dermis. Melanocytes produce melanin, giving colour to the skin. When skin is exposed to the sun, the melanocytes generate more melanin and cause the skin to tan or darken. Sometimes melanocytes cluster together and form moles, also called nevi. Moles are common and are usually not cancerous. However, sometimes the cells begin to grow uncontrollably turning into a melanoma.

Epidemiology

Melanoma is a worldwide problem and its incidence continues to rise globally (Ferlay et al., 2013; Geller, 2009; World Health Organization, 2018). Melanoma is the 5th most commonly diagnosed cancer among males and 7th among females in the United States and the 7th in Canada (among both sexes) (American Cancer Society, 2018a; Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017). This disease represents 5% (US) and 3.5% (Canada) of all new cancer diagnoses, however these statistics do not account for differences between age groups. Melanoma accounts for 7% of all cancer diagnoses in individuals 15-29 years of age, contributing to 4% of cancer-related deaths in this subpopulation, and for 6% of cancers in individuals between 30 and 49 years of age (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017).

It is estimated that currently 921 780 Americans and 39 490 Canadians are living with the

diagnosis and lifetime risk of developing melanoma is about 2% in the United States and 1.6% in

Canada (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017; Howlader

et al., 2013). Moreover, its incidence in North America has been on the rise for decades,

increasing in the recent years annually by 2.4% in Canada and by 2.7% in the United States

(American Cancer Society, 2018a; Canadian Cancer Society's Advisory Committee on Cancer

Statistics, 2017). To put those numbers into perspective it is worth noting that the current

lifetime risk of developing a melanoma is 1 in 74 female and 1 in 56 male Canadians and 1 in 42

females, 1 in 27 males in the United States, whereas in the 1930s it was about 1 in 1500

individuals in North America (American Cancer Society, 2018a; Canadian Cancer Society's

Advisory Committee on Cancer Statistics, 2017; Rigel, 2010). Additionally, it seems that people

do not follow the recommendations for sun protection enough, which may lead to increasing the

incidence of melanoma even further. For instance, national surveys found that in 2006,

Canadians spent more time in the sun without increasing their sun protection behaviours than in

1996 (National Skin Cancer Prevention Committee, 2010). It is estimated that if such trends were

to continue, a 72% increase in the number of new melanoma cases diagnosed in Canada would

be expected during the five-year period of 2028-2032, compared to 2003-2007 (Canadian Cancer

Society's Advisory Committee on Cancer Statistics, 2015).

Melanoma accounts for 75-90% of all deaths attributed to skin cancer and every hour a

person dies from it in the United States (American Academy of Dermatology, 2018d; Garbe et

al., 2010; Trask et al., 2001). Currently the 5-year survival rates of patients diagnosed with

melanoma exceed 90% and the probability of dying from the disease has slightly decreased over

the years for any given patient. However, the incidence continues to rise annually by 2-3%

(American Cancer Society, 2018a; Canadian Cancer Society's Advisory Committee on Cancer

Statistics, 2017; Siegel, Miller, & Jemal, 2016). Due to the increase in incidence the overall

number of deaths due to melanoma has been on the rise. Unlike breast and colon cancers, which

have been showing annually decreasing mortality rates over the past 20 years in the USA (-2.5

and -2.2%, respectively), melanoma mortality rates have remained relatively stable (Mitchell &

Leslie, 2013). Consequently, the US Department of Health and Human Services has set a goal of

reducing melanoma-related mortality by 10% by year 2020 as a part of the "Healthy People"

initiative (US Department of Health and Human Services, accessed 2018).

Staging and prognosis

        The 5-year survival rate from melanoma is over 90% (American Cancer Society, 2018a;

Howlader et al., 2013), however the likelihood of dying from melanoma varies widely depending

on the stage of the disease at diagnosis. The stages of melanoma are established based on the

tumour thickness, ulceration and rate of mitosis of the cancerous cells (Balch, Gershenwald,

Soong, Thompson, Atkins, Byrd, Buzaid, Cochran, Coit, & Ding, 2009). There are 4 stages of

melanoma (I, II, III and IV), as well as a "pre-melanoma" stage 0 with the higher stage indicating

more advanced cancer (Balch, Gershenwald, Soong, Thompson, Atkins, Byrd, Buzaid, Cochran,

Coit, & Ding, 2009). Stage 0, also called *in situ,* is constrained to the epidermis, the outer layer

of the skin, and is non-invasive with 100% survival rate if treated before progression (American

Cancer Society, 2016; Balch, Gershenwald, Soong, Thompson, Atkins, Byrd, Buzaid, Cochran,

Coit, & Ding, 2009). Each stage from I to IV is further divided into sub-stages A, B and

sometimes C, with a higher letter indicating more advanced disease and typically a poorer

prognosis. Stage I is associated with 86 to 95% five-year observed survival rate, stage II: 40 to

67%, stage III: 24 to 68% and stage IV: 15 to 20% decreasing further to 10-15% for the 10-year

observed survival rate (American Cancer Society, 2016; Balch, Gershenwald, Soong, Thompson, Atkins, Byrd, Buzaid, Cochran, Coit, & Ding, 2009).

Sociodemographic variables associated with melanoma

  Race. The lifetime probability of developing melanoma among Whites is 2.6%, among Hispanics it is .58%, and among the black population in North America it is 0.1% (American Cancer Society, 2018c). Individuals with fair skin are at highest risk for developing skin cancers. However, individuals with darker skin are more likely to die from melanoma. For example, the 5-year survival rate of African Americans is only 69% and it has in fact declined (from 79%) since the 1980s (American Cancer Society, 2018a).

  Age. The risk of being diagnosed with melanoma increases with age. The median age at diagnosis is 61. However, melanoma is more common in younger individuals than other human cancers. About 35% of individuals diagnosed with melanoma are under 55 years of age (American Cancer Society, 2018c; Howlader et al., 2013). The median age at death is 69 (Howlader et al., 2013).

  Sex. In addition to age, sex is also a risk factor for melanoma as men are more likely to be diagnosed (27 males vs. 17 females per 100 000 people in the USA and 21 vs. 16 per 100 000 individuals living in Canada) (Howlader et al., 2013) (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013; Howlader et al., 2013) as well as experience a recurrence (21% vs. 9% in females) (Jones et al., 2013). The survival rates differ as well with 85% of males and 92% of females being still alive 5 years after the diagnosis (*cf.* observed survival: 75% and 85% for males and females, respectively) (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013, 2014). While it has been speculated that the difference in melanoma-specific survival may be due to the fact that men are more likely to be diagnosed with more

advanced tumours, which carry a higher risk of mortality (Reyes Ortiz, Freeman, Kuo, &

Goodwin, 2007; Van Durme et al., 2000), recent studies controlling for the cancer stage (tumour

thickness, histological subtype, metastasis) and the melanoma location on the body show that

male sex was an independent predictor of higher mortality (Gamba, Clarke, Keegan, Tao, &

Swetter, 2013; Pollack et al., 2011).

Education. In the Unites States, the levels of mortality due to melanoma have been

declining in most recent years but only among individuals with the highest educational

attainment, i.e., >13 years of schooling (Cokkinides, Geller, & Jemal, 2012). Dr. Cokkinides

(2012) proposed that the findings of her team may be explained by lower awareness of

melanoma, less access to health care as well as occupations requiring prolonged exposure to sun

radiation among individuals with lower educational attainment (Simon, 2012).

Risk factors

Sun exposure. One of strongest risk factors for developing melanoma is sun exposure

(Whiteman et al., 2006). Different types of sun exposure (chronic, intermittent, acute) appear to

be associated with the development of different types of skin cancer (melanoma, basal cell

carcinoma or squamous cell carcinoma). For melanoma, intermittent exposure to sun increases

the odds of future diagnosis the most (Odds Ratios, ORs: 1.6-1.7). Intermittent sun exposure is

defined as sporadic and is typically associated with recreational activities, especially among

individuals who usually spend their days indoors and once in a while spend some time outside

during a weekend or vacation, not allowing the skin the time to slowly get used to the UV

radiation. Chronic, i.e., consistent and repetitive sun exposure, appears less likely to contribute to

the growth of melanoma and may even be associated with a decreased risk (ORs: .73-.86)

(Elwood & Jopson, 1997; Gandini, Sera, Cattaruzza, Pasquini, Picconi, et al., 2005; Gandini, Sera, Cattaruzza, Pasquini, Zanetti, et al., 2005; Nelemans, Rampen, Ruiter, & Verbeek, 1995).

Additionally, a history of severe sunburns has been linked to the development of melanoma (Elwood & Jopson, 1997; Kennedy, Bajdik, Willemze, De Gruijl, & Bouwes Bavinck, 2003). The link between cumulative lifetime sun exposure and melanoma diagnosis is unclear as different researchers report conflicting findings (Kennedy et al., 2003; Whiteman et al., 2006). Last but not least, there may be an interaction between sun exposure and melanoma location on the body as there is some research indicating that intermittent exposure may increase the risk of melanoma on the trunk (but not head or neck), while chronic exposure may increase the risk of melanoma on the head and neck (but not on the trunk) (Caini et al., 2009; Whiteman et al., 2006).

Exposure to ultraviolet radiation (UVR). Skin exposure to ultraviolet radiation (including artificial light in tanning beds) has been linked to development of melanomas (Le Clair & Cockburn, 2016; Thomas & Hensin, 2007). There are multiple pathways through which UVR predisposes an individual to melanoma including DNA damage through the formation of dimeric photoproducts, gene mutations, oxidative stress, inflammation, and immunosuppression (Kanavy & Gerstenblith, 2011).

Other environmental factors. There are a number of additional potential risk factors for melanoma associated with different occupational requirements and environmental variables including exposure to solvents (Wennborg et al., 2001), heavy metals (Beane Freeman, Dennis, Lynch, Thorne, & Just, 2004), electromagnetic fields (Tynes, Klaeboe, & Haldorsen, 2003), PVC - polyvinyl chloride (Langard, Rosenberg, Andersen, & Heldaas, 2000; Lundberg, Gustavsson,

Holmberg, Molina, & Westerholm, 1993) and PCB – polychlorinated biphenyl (Sinks, Steele,

Smith, Watkins, & Shults, 1992).

In addition to the above-mentioned, mostly isolated, studies two potentially related

factors have been repeatedly linked to the risk of melanoma: (a) exposure to ionizing radiation

(Freedman et al., 2003; Sigurdson et al., 2003; Sont et al., 2001; Telle-Lamberton et al., 2004)

and (b) being a member of an airline flight crew. The latter has been consistently associated with

mildly elevated incidence of melanoma (Standardized Incidence Ratio, SIR = 1.5 to 2.9) and

greater mortality due to the disease (Standardized Mortality Ratio, SMR = 1.5 to 1.8), as

compared to the general population (Band et al., 1996; Blettner et al., 2003; Gundestrup &

Storm, 1999; Haldorsen, Reitan, & Tveten, 2001; Hammar et al., 2002; Irvine & Davies, 1999;

Pukkala et al., 2003). This last finding has been explained in terms of potentially more frequent

leisure-time exposure to the sun as well as the ionizing radiation. However, the debate regarding

the potential causality of the elevated melanoma risk among airline flight crew members is

ongoing (Blettner et al., 2003; Haldorsen et al., 2001; Shore, 1990). Finally, low level of serum

vitamin D may be linked to greater susceptibility to melanoma as well as to thicker tumours and

lower 5-year survival (Field, Davies, Bishop, & Newton-Bishop, 2013; Newton-Bishop et al.,

2009; Sondak, McIver, & Kanetsky, 2016).

Phenotype. A person's skin colour, eye colour as well as density of freckles have all

been associated with the development of melanoma (Gandini, Sera, Cattaruzza, Pasquini,

Zanetti, et al., 2005). Melanoma is much more common among light-skinned people, who

represent a great majority of all melanoma cases. In fact, melanoma is 20 times more common

among individuals of Caucasian descent than among African Americans affecting about 1 in 50

White people and 1 in 1 000 Black people (American Cancer Society, 2018c; Canadian Cancer

Society's Advisory Committee on Cancer Statistics, 2013; Howlader et al., 2013). Gandini and

colleagues (2005) reported in their meta-analysis that having blue or green eyes as opposed to

brown is associated with a greater relative risk of developing melanoma (Relative Risk, RR = 1.5

and 1.6 respectively). The same authors also reported a link between high density of freckles and

melanoma (RR = 2.1) (Gandini, Sera, Cattaruzza, Pasquini, Zanetti, et al., 2005).

A high number of nevi (moles) has been strongly associated with the diagnosis of

melanoma (Newton-Bishop et al., 2010). For instance, having over a 100 nondysplastic

melanocytic nevi (i.e., regular moles) has been associated with a ten-fold relative risk of

developing melanoma (Holly, Kelly, Shpall, & Chiu, 1987). However, not only the number but

also a larger size of moles is positively correlated with intermittent sun exposure, suggesting

there may be an interaction effect between these risk factors (Newton-Bishop et al., 2010).

Further, high mole counts are associated with melanoma even on body sites usually not exposed

to the sun (Caini et al., 2009). Even though higher numbers of typical and atypical nevi have

been associated with melanoma, the association appears to be stronger for atypical/dysplastic

moles. Atypical nevi can be found in about 2 to 53 % of the general population depending on the

assessment method (clinical observation or histological report) with more accurate reports

reporting a range of 2 to 8% (Friedman et al., 2009). An individual with a large number of moles,

including at least 1 that is atypical (i.e., dysplastic) and 1 that is at least 8 mm in diameter would

be considered to have "atypical mole/dysplastic nevus syndrome", which is considered by some

to be among the most important phenotypical risk factors for melanoma (Silva, Sa, Avila,

Landman, & Duprat Neto, 2011). The estimated 10-year cumulative risk for developing

melanoma in individuals with this syndrome was 11% as compared to less than 1% in a control

population (Marghoob, Kopf, Rigel, & et al., 1994).

Genotype. Several recent studies focused on identifying potential genes contributing to the increased risk for melanoma. For instance, Newton-Bishop and colleagues identified single nucleotide polymorphisms (SNP) on chromosomes 9 and 22 as being linked to high numbers of nevi as well as larger nevi and those on chromosome 6 associated only with large nevi. However, these polymorphisms explained only a small proportion of melanoma risk and nevus phenotype, which led the authors to conclude that "several nevus genes likely remain to be identified" (Newton-Bishop et al., 2010). In addition to the entire chromosomes identified as carrying some genes related to the number and size of nevi research has also pointed to specific gene mutations carrying a higher risk of developing a melanoma. For example, mutations in CDKN2A, a tumour-suppressing gene, account for 3.3% of melanoma cases without family history and up to 100% of cases with a strong family history of the disease (Bishop-Newton, Harland, Randerson-Moor, & Bishop, 2007; Goldstein et al., 2006; Nikolaou et al., 2011). Further, researchers identified a trend in that the more family members with melanoma the more likely an individual is to carry the mutation predisposing them to this cancer (Bishop-Newton et al., 2007; Goldstein et al., 2006; Nikolaou et al., 2011). In families with two cases of the disease who have other features of hereditary melanoma, such as an age at diagnosis below 50 years or one or more individuals diagnosed with multiple primary melanomas, the frequency of CDKN2A mutations is as high as 22% (Maubec et al., 2012). Indeed, individuals with CDKN2A mutations are on average statistically much younger at diagnosis (39 years vs. 54 years) as compared to other melanoma patients and they have a significantly higher 5-year cumulative incidence of a second melanoma (23.4% in mutation carriers vs. 2.3% in mutation-negative control subjects) (van der Rhee et al., 2011).

The recent technological advances have allowed the identification of new genes involved in melanoma susceptibility: breast cancer 1 (BRCA1), BRCA1-associated protein 1 (BAP1), and telomerase reverse transcriptase (TERT) (De Simone, Valiante, & Silipo, 2017). Additionally, the neurotrophin Neuritin1 (NRN1) has been recently identified as a potential early marker of melanoma as it is involved in melanoma migration, attachment independent growth, and vascular mimicry (Bosserhoff, Schneider, Ellmann, Heinzerling, & Kuphal, 2017).

Several other genes have been identified as potential genetic "modifiers" for melanoma as they code for other risk factors, such as red hair colour, tendency of the skin to burn instead of tanning, etc., but they may also carry some degree of independent risk. They include mutations of the MC1R (Box et al., 2001; Kanetsky et al., 2010), E318K variant of the MITF gene (Yokoyama et al., 2011), and mutations in BRCA2 gene (Kadouri et al., 2009).

Immunosupression. An additional risk factor for developing melanoma is being a recipient of immunosuppressive therapy. The rates of melanoma among patients who underwent immunosupression are 1.6 to 8 times higher than those of the general population (Dinh & Chong, 2007; Le Mire, Hollowood, Gray, Bordea, & Wojnarowska, 2006; Leveque et al., 2000).

Family history of melanoma. Having a family member with a diagnosis of melanoma increases one's risk of developing this cancer (Lucchina, Barnhill, Duke, & Sober, 1995). For instance, Brandt and associates (2011) conducted a family cancer registry study involving over 20 000 individuals diagnosed with melanoma and reported an incidence ratio of 2.62 for offspring of individuals with melanoma and 2.94 for siblings (Brandt, Sundquist, & Hemminki, 2011). Similarly, Hemminki and colleagues (2003) examined a Swedish Family Cancer Database comprised of over 10 million individuals among which 24 818 invasive and 5 510 in situ melanomas were found. Offspring of parents with melanoma were 2.4 times more likely to be

diagnosed (SIR=2.40), and siblings of individuals with melanoma were nearly 3 times as likely

to be diagnosed themselves (SIR=2.98). When both a parent and a sibling had a history of

melanoma the risk of melanoma was even higher (SIR=8.92) (Hemminki, Zhang, & Czene,

2003). Offspring of parents with multiple melanomas had an almost 62 times higher risk of

developing melanoma (SIR=61.78), compared to the general population (Hemminki et al., 2003).

        The familial susceptibility to melanoma is likely due to a genetic predisposition such as a

hereditary CDKN2A mutation (Goldstein et al., 2006), which may vary by population. For

example, Bishop and colleagues' (2002) research comparing the penetrance of CDKN2A

mutations in various locations across Europe, USA and Australia showed that the average

penetrance, i.e., the number of individuals carrying the mutations who had developed melanoma,

was 30% by age 50 and 67% by age 80. However, there was a significant variation across

locations. Namely, by 50 years of age CDKN2A mutation penetrance reached 13% in Europe,

50% in the United States, and 32% in Australia while by age 80 it increased to 58% in Europe,

76% in the United States, and staggering 91% in Australia (Bishop et al., 2002). Based on the

fact that the penetrance varied with the population incidence rates the authors concluded that the

same factors (e.g., environmental), that affect incidence may also mediate the penetrance of the

CDKN2A mutation (Bishop et al., 2002).

        Personal history of non-melanoma skin cancer (NMSC). Individuals diagnosed with

non-melanoma skin cancers (e.g., Basal Cell Carcinomas or Squamous Cell Carcinomas) are

more likely to develop a melanoma. A personal history of NMSC has been associated with an

increased risk of melanoma in men (Relative Risk, RR = 1.99, Age-Standardized Risk, ASR =

116 per 100 000 person-years) as well as in women (RR = 2.58, ASR = 79 per 100 000 person-

years) (Song et al., 2013). Similarly, Chen and colleagues (2008) found that the elevated risk of

developing melanoma remains even after adjusting for other potential risk factors such as age, sex, body mass index, cigarette smoking, education, skin type, and sunburn history.

Personal history of melanoma. A past diagnosis of melanoma is a strong risk factor for developing subsequent lesions (Burden et al., 1994; Geller, Swetter, Brooks, Demierre, & Yaroch, 2007; Uliasz & Lebwohl, 2007). In fact, up to 16 out of 100 patients diagnosed with melanoma develop subsequent tumour(s) within 9 years of the first diagnosis (Ferrone, Ben Porat, Panageas, Berwick, Halpern, Patel, & al., 2005; Jones et al., 2013; Kang, Barnhill, Mihm, & Sober, 1992; Manganoni, Farisoglio, Tucci, Facchetti, & Calzavara Pinton, 2007; Savoia, Quaglino, Verrone, & Bernengo, 1998; Stam-Posthuma, Van Duinen, Scheffer, Vink, & Bergman, 2001). For patients who had 2 primary melanomas, the 10-year risk of developing a third lesion has been estimated at 27.7% (Doubrovsky & Menzies, 2003).

Prevention of melanoma

Primary and secondary prevention

Given the increasing incidence of melanoma and the lack of a cure for advanced disease it is crucial to implement effective, feasible, and wide-reaching preventative strategies. The *primary prevention* of melanoma (i.e., the prevention of developing a first melanoma in the general, non-affected population) focuses on educating the public on the importance of avoiding excessive sun exposure and indoor tanning, preventing sunburns through staying indoors at peak hours of sun activity, wearing sunglasses and clothing protecting the skin as well as using appropriate sunscreen (Edman & Wolfe, 2000). In contrast, *secondary prevention* aims for the early detection of a disease, in this case melanoma. It involves increasing the awareness for early signs of the tumour and engagement in practices favouring early detection such as clinical skin exams (performed by a physician or another dermatology-trained healthcare professional) and/or

skin self-exams – SSE, performed by the patient (Markovic et al., 2007). Educational campaigns increasing awareness of the importance of noticing changing nevi and prompt self-referral to physicians are a good example of efforts regarding the secondary prevention of melanoma (Edman & Wolfe, 2000; Schwartz et al., 2002).

Individuals with a prior diagnosis of melanoma are at lifelong increased risk for subsequent primary melanomas, as compared to the general population. As such, secondary prevention is particularly important for this group (Doubrovsky & Menzies, 2003; Jones et al., 2013). Interventions for individuals previously diagnosed with melanoma focusing on early detection and timely treatment of subsequent melanomas may have the most significant impact on reducing melanoma-related mortality (Geller et al., 2007; Weinstock, 2006). The clinical skin exams are very important as the physicians may be able to detect melanomas at earlier stages allowing for more timely and effective treatment (Carli et al., 2003; Epstein, Lange, Gruber, Mofid, & Koch, 1999; Schwartz et al., 2002). However, clinical exams are increasingly less likely to include an examination of the entire body of the patient and can miss 1 in 3 melanomas (Aldridge, Naysmith, Ooi, Murray, & Rees, 2013). Further, given that only 13 to 16% of individuals from the general population report having their skin checked by a physician in the previous year it is not surprising that the majority of melanomas are first noticed by non-clinicians including patients themselves, their friends, relatives and other people patients comes in contact with, such as massage therapists, hair dressers, cosmetologists, beauticians, etc. (Carli et al., 2003; Coups, Geller, Weinstock, Heckman, & Manne, 2010; Hamidi, Cockburn, & Peng, 2008; Pollitt et al., 2009; Schwartz et al., 2002; Titus, 2013). Research suggests that checking one's skin for changes may increase the likelihood that an individual will consult a physician before the tumour develops to more advanced stages (Carli et al., 2003; Titus, 2013).

Consequently, the practice of skin self-examination may be an important step toward early

diagnosis, timely treatment, and reduced melanoma-related mortality (Berwick, Begg, Fine,

Roush, & Barnhill, 1996; Berwick et al., 2016; Geller et al., 2007; Weinstock, 2006).

Raising melanoma awareness in the general population

In the recent years, worldwide efforts have been made to increase awareness of

melanoma and skin exams in the general population, mostly in the countries with predominantly

fair-skinned citizens (Edman & Wolfe, 2000; Schwartz et al., 2002). For instance, Australia has a

relatively long history of awareness-raising campaigns starting with the well-known "Slip, Slop,

Slap" slogan in the early 1980s, which encouraged the general public to "Slip on a shirt, slop on

sunscreen, and slap on a hat" (Montague, Borland, & Sinclair, 2001). The campaign was very

successful at introducing the ideas relative to sun-protection to the general public as the "Slip,

Slop, Slap" message has become a part of modern Australian phraseology and continues to be re-

ran once every few years (Cancer Council Victoria, 2018b). More recently, the National Skin

Cancer Awareness Campaign sponsored television, cinema and radio ads, printed materials as

well as internet and outdoor advertising in order to discourage the sun exposure (Australian

Governement: Department of Health and Aging, 2010). The campaign took place annually

during four consecutive summers with the initial target audience of children and adolescents in

phase I and II (ages 13 to 17) and young adults (18 to 24 years of age). Subsequent population

surveys showed a few percent decrease in deliberate tanning and burning and an increase in sun-

protective behaviours ranging from wearing a hat, sunglasses and protective clothing to using

sunscreen (Australian Governement: Department of Health and Aging, 2010).

Similarly, the Cancer Institute of the New South Wales sponsored a campaign under the

slogan "The Dark Side of Tanning" promoting the message that "there is nothing healthy about a

tan" (Cancer Institute of the New South Wales, 2017). The messages targeted mostly young

people via televised and print advertisements featuring young women and men outdoors

developing cancerous cells as they tan. The campaign aimed to increase the knowledge about

melanoma as well as behaviours associated with both primary and secondary prevention. The

campaign was active every summer from 2007 until February 2015 (Cancer Council Victoria,

2018a).

       Among the African countries South Africa appears to be the only one invested in raising

melanoma awareness, which is likely due to the fact that a significant portion of the population

in this country is fair-skinned and as such at higher risk of developing this skin cancer. Indeed,

the incidence of melanoma in South Africa may be as high as in Australia, i.e., one of the highest

in the world, and has been increasing steadily over the recent years (Saxe et al., 1998; South

African Melanoma Advisory Board, 2018). Despite the high incidence of melanoma there is little

evidence of efforts to increase primary prevention in the South African population. A notable

exception was a 1-day privately-funded event in 2010, "Protect your skin and save your life!",

during which dermatologists visited popular athletes during a sports event. Together they raised

awareness of the disease, while the physicians offered free skin screening to the general public

(South African Melanoma Advisory Board, 2010).

       In Europe, in addition to some small-scale national efforts to increase awareness of

melanoma (e.g., offering informational leaflets to the general public), there is also a pan-

European melanoma prevention campaign "Euromelanoma" organized by the European

Association of Dermato-Oncology (EADO) (Euromelanoma, 2018). Initiated in Belgium in

1999, the campaign has now been active in 33 European countries. For at least one day each

year, the general public has the opportunity to obtain a free-of-charge screening of their moles by

volunteering dermatologists and so far over 450 000 individuals were screened for skin cancer as

a part of the campaign (Euromelanoma, 2018). Participants are also provided with printed

materials to facilitate their own skin self-examination in the future. Research suggests that

Euromelanoma day has had a significant impact on melanoma prevention and early diagnosis

and has positively influenced public health attitudes toward regular skin examination and the

implementation of melanoma preventative strategies in participating countries (Conejo-Mir et al.,

2005; Lieberherr et al., 2017; Paoli, Danielsson, & Wennberg, 2009; Stratigos et al., 2012;

Stratigos et al., 2007; van der Leest et al., 2011).

In North America, similar campaigns have been taking place annually in the recent years.

For instance, in 2012 the Canadian Dermatology Association (CDA) officially adopted

"Melanoma Monday" as an annual event taking place every first Monday of May to be filled

with activities to raise awareness about the seriousness of melanoma, inform Canadians about the

dangers of skin cancer, how they can prevent it as well as learn to identify suspicious changes on

their skin. In the United States that same day has been named "Melanoma Black Monday" and

different activities, such as giving out sun block or free screening, i.e., clinical skin

examinations, coordinated by the American Academy of Dermatology (AAD) have been taking

place all over the country to raise awareness of melanoma. The "SPOT skin cancer" initiative of

the AAD "aims to educate the public about skin cancer and motivate individuals to make

positive behaviour changes to prevent and detect skin cancer" (American Academy of

Dermatology, 2018a).

The campaigns have been shown to increase melanoma awareness but do they improve

patients' health outcomes? A recent review by Brunssen and colleagues (2017) suggests that

with implementation of skin cancer screening for the general population, incidence of in situ and

invasive skin cancer increased, which is likely due to *greater detection rates* of existing skin

cancers. Furthermore, detection of thin tumours increased, while detection of thick tumours

decreased suggesting *earlier detection*. There may even be a *decrease in melanoma-related*

mortality with research finding less deaths than expected (Brunssen, Waldmann, Eisemann, &

Katalinic, 2017). The final question is whether these campaigns represent a financial investment

or an expense. Research suggests that the educational campaigns have been very cost-effective in

that they prevent health care spending on treatment of more advanced cancers (Doran et al.,

2016; Losina, Walensky, Geller, & et al., 2007).

Current recommendations and clinical guidelines for melanoma prevention

The American and the Canadian health agencies provide information for the general

public regarding primary prevention of melanoma, which includes information on the dangers of

UV radiation along with tips on how to avoid harmful UV rays (i.e., wearing protective clothing,

staying in the shade between 11am and 3pm, using UV index forecast as a guide for when the

protection from the sun is the most important, avoiding tanning beds) as well as basic

information regarding melanoma (Centers for Desease Control and Prevention, 2018;

Government of Canada, 2017).

In contrast to the guidelines on sun protection, the official national prevention guidelines

regarding skin examinations remain conservative, i.e., neither recommending nor advising

against SSE. The reason for this neutral stance vis-à-vis SSE is the paucity of research available

to draw definite conclusions about the efficacy of population-wide skin examinations as there is

a paucity of randomized controlled trials and large scale, well-controlled longitudinal studies

(Canadian Task Force on the Periodic Health Examination, 1994; U.S. Preventive Services Task

Force, 2016). Despite the more conservative national guidelines, professional dermatology and

cancer associations as well as patient organizations strongly suggest that individuals at high risk (and in some instances *everyone*) should perform skin self-exams and self-refer to their physicians as needed (American Academy of Dermatology, 2018c; American Cancer Society, 2018b; Canadian Dermatology Association, 2018; From et al., 2007; Melanoma Network of Canada, 2018; Save Your Skin Foundation, 2018; Skin Cancer Foundation, 2018). Additionally, there is a consensus in terms of recommending both clinical and skin self-examinations for individuals who have already been diagnosed with melanoma (Alberta Health Services, 2013; From et al., 2007). For instance, the National Comprehensive Cancer Network (NCCN), "a not-for-profit alliance of 27 leading [American] cancer centers devoted to patient care, research, and education" put forth clinical guidelines stating that upon completion of the melanoma staging and treatment procedures all patients should be advised to examine their own skin on a monthly basis in addition to receiving regular exams by trained physicians (Coit et al., 2009; National Comprehensive Cancer Network, 2018). In sum, certain organizations advocate for SSE and annual skin exams performed by physicians for the general population (American Cancer Society, 2018b; Skin Cancer Foundation, 2018), some restrict such recommendations to individuals at increased risk for melanoma (Bichakjian et al., 2011; Coit et al., 2009; National Comprehensive Cancer Network, 2018), while others do not endorse any routine screening for melanoma at all (Helfand, Mahon, Eden, Frame, & Orleans, 2001; Robinson & Jablonski, 2018; U.S. Preventive Services Task Force, 2016).

Since the national-level, conservative recommendations had been published, some suggestions for revising them based on the newest data have been put forth. The main argument brought forward in an effort to change those guidelines is related to the fact that the national-level recommendations are based not on the existing evidence showing that skin exams are

ineffective but on the lack of large-scale longitudinal controlled trials proving their effectiveness.

However, the cost of such randomized controlled trials requiring about 800 000 individuals to be

followed for several years is prohibitive, while smaller yet rigorous RCTs with populations at

high risk are already being conducted and could be used to inform the recommendations for

screening (Curiel-Lewandrowski, Chen, & Swetter, 2012; Mitchell & Leslie, 2013).

Early detection of melanoma and its benefits

Despite the heterogeneity of current screening recommendations, there is a significant

body of research suggesting that skin self-examinations play an important role in the early

detection of melanoma. First, up to 87% of melanomas are first noticed by patients themselves

and people in close proximity to them, not by physicians (Brady et al., 2000; Carli et al., 2003;

Coups et al., 2010; Epstein et al., 1999; Hamidi et al., 2008; McPherson et al., 2006; Pollitt et al.,

2009; Schwartz et al., 2002; Titus, 2013). Second, checking one's own skin for changes can

improve the odds of seeking medical consultation before the tumour progresses to more

advanced stages (Carli et al., 2003; Titus, 2013). For instance, Berwick and colleagues (1996)

conducted a large-scale population-based case-control study in which patients who conducted

SSE following the instructions closely, presented with significantly thinner melanomas than

participants who did not perform SSE (Berwick et al., 1996). Moreover, SSE was associated with

a decreased risk for a second primary melanoma and more advanced disease. Most significantly,

SSE reduced melanoma-related mortality by 63% (Berwick et al., 1996). Additionally, a follow-

up 20 years later showed a 25% lower risk of melanoma death for those who performed SSE

(Paddock et al., 2016). A different project involving over 2 000 patients diagnosed with

melanoma (stages I through IV) showed that early detection of recurrence is associated with a

higher probability of survival later on (Garbe et al., 2007). Recurrence is a serious concern as it

occurs in a significant proportion of the patients (Ferrone, Ben Porat, Panageas, Berwick, Halpern, Patel, & al., 2005; Jones et al., 2013). For instance, in a sample of 1 062 patients 1 in 5 developed a second melanoma (Dalal et al., 2008). It is noteworthy that as melanoma survivors these patients were presumably followed more closely by their dermatologists than unaffected individuals from the general population and yet, the subsequent melanoma was most often self-detected (55% self-detection vs. 45% physician detection) (Dalal et al., 2008). Furthermore, self-detection of the melanoma, but not physician-detection, was an independent predictor of survival (Dalal et al., 2008).

Prevalence of skin self-examination

There is a wide range of reports on the practice of skin self-examination (prevalence range: 9 – 75%), with the majority of research reporting 15-30% prevalence of SSE (Berwick et al., 1996; Carli et al., 2003; Coups et al., 2016; Glenn, Chen, Chang, Lin, & Bastani, 2017; Kasparian et al., 2012; Kasparian et al., 2010; K. A. Miller et al., 2015; Mujumdar et al., 2009; Oliveria et al., 2004; Rat et al., 2014; Weinstock et al., 1999). These differences may be due to the different operationalization of SSE across studies. For instance, a research project assessing SSE with a single question and a binary "yes/no" answer format is likely to report higher levels of SSE (Kasparian et al., 2012) than a study using a more comprehensive definition including the number of body parts examined, frequency of the practice, etc. (Aitken et al., 2004; Berwick et al., 1996; Carli et al., 2003; Rat et al., 2014; Weinstock et al., 1999). In fact, when research distinguishes between whole-body examination versus partial SSE the prevalence rates reported for these variables vary significantly (Aitken et al., 2004). Similarly, research assessing SSE on monthly or bimonthly bases tends to report lower SSE rates as compared to research assessing annual practice or an engagement in SSE over the participant's lifetime (Aitken et al., 2004;

Mujumdar et al., 2009). Additional consideration when attempting to understand a wide range or patient reported SSE practice may be the location of the study, as typically research conducted in Australia reports the highest rates of self-exams, while European and North American studies report a much lower prevalence of SSE. This may be due to this country's efforts to promote sun protection, melanoma-awareness as well as to normalize routine skin checks (see section on educational campaigns, p. 30.)

Predictors of skin self-examination

There are several factors, which predict the engagement in SSE. First, geography and race seem to interact in predicting SSE as fair-skinned individuals living in parts of the world with greater sun exposure are more likely to check their own skin for suspicious changes (Kasparian et al., 2012). For instance, Kasparian and colleagues (2012) reported that the global rates of SSE are highest in Australia and the United States, followed by Europe, within which Southern populations reported higher rates of SSE practice than individuals from the Northern countries. This phenomenon may be explained by an associated higher incidence of melanoma but also by social norms and levels of melanoma-awareness (Kasparian et al., 2012). Indeed, Australia is a good example of a country with consistently high prevalence of SSE practice as well as one with the most intensive and long-lasting melanoma awareness-raising campaigns. It can be contrasted with South Africa, where the incidence is equally high but the awareness as well as the SSE practice are likely to be low (South African Melanoma Advisory Board, 2018). Second, other sociodemographic characteristics positively associated with SSE include being female, being younger, having a higher level of education and greater income, as well as living with a partner (Aitken et al., 2004; Carli et al., 2003; Manne & Lessin, 2006; K. A. Miller et al., 2015; Robinson et al., 2002; Robinson et al., 1998).

Additionally, melanoma-related risk factors such as the number of nevi as well as having

had dermatology visits with skin biopsies and a diagnosis of a skin carcinoma in the previous 3

years have also been linked to greater likelihood of engaging in SSE (Mujumdar et al., 2009;

Robinson et al., 2002). Similarly, having a family member who was diagnosed with melanoma or

having a personal history of melanoma has been associated with more SSE practice as compared

to the general population (Glenn et al., 2017; Kasparian et al., 2012; Kasparian et al., 2010).

Further, cognitive factors associated with skin self-examination include higher perceived risk of

melanoma (e.g., due to the family history or the phenotype putting the person at risk), perceived

benefits of the practice and barriers to SSE, higher SSE-related self-efficacy and a greater

knowledge about melanoma and SSE (Glenn et al., 2017; Hay et al., 2006; Kasparian et al.,

2012; Kasparian et al., 2010; Manne et al., 2004; Manne & Lessin, 2006; Mujumdar et al., 2009;

Phelan, Oliveria, Christos, Dusza, & Halpern, 2003; Robinson et al., 2002; Robinson et al.,

1998). Additionally, the level of personal comfort with being assisted by one's partner in

performing SSE has emerged as a positive predictor of the practice (Robinson, Turrisi, &

Stapleton, 2007a, 2007b). Moreover, some limited recent research suggests that use of tanning

beds (associated with higher risk of melanoma) may be linked to more skin self-exams, possibly

due to users' understanding that they expose themselves to greater risk based on warning labels

affixed to tanning devices (Morris, Luke, & Perna, 2018). Lastly, being given a recommendation

or instructions on SSE performance from one's nurse or physician also correlates positively with

the practice of skin self-examination (Aitken et al., 2004; Kasparian et al., 2010; Rat et al., 2014;

Robinson et al., 1998; Robinson et al., 2007b).

Interventions aiming to improve the practice of skin self-examination

Two recent systematic reviews showed that interventions aimed at teaching patients about SSE are associated with increases in SSE practice (Henrikson et al., 2018; Wu et al., 2016). Given that research has identified a number of predictors of skin self-examination, several intervention studies have been conducted in order to maximize the likelihood of effective SSE performance. For instance, Oliveria and colleagues conducted a longitudinal research project with 100 individuals at risk for developing melanoma (defined as having 5 or more dysplastic nevi), which involved an educational intervention delivered by a nurse (Hay et al., 2006; Oliveria et al., 2004; Phelan et al., 2003). Participants were assigned to two groups: one group received the teaching intervention along with a personalized photobook with pictures of the patient's body and one group received the same education but without the photobook. The mean scores for melanoma knowledge, awareness of skin changes and the confidence in the ability to perform SSE increased over time in both groups (Phelan et al., 2003). The intervention was associated with a significant increase in SSE performance within the following 4 months in both groups while the gains in the photobook condition were more than twice as large as those in the control group (increase of 51% vs. 17.6%) (Oliveria et al., 2004). Self-efficacy significantly mediated the relationship between the photobook use and SSE at the 4-month follow-up (Hay et al., 2006). Indeed, a review of the literature on the role of the visual materials in teaching SSE suggests that providing images during the education such as pictures, drawings, mole-mapping diaries or videos positively affects SSE-related knowledge, attitudes toward the practice and the performance itself (McWhirter & Hoffman-Goetz, 2013).

Another longitudinal project of 4-months duration was conducted with 130 individuals previously diagnosed with melanoma, who received educational materials and skills training

from a research assistant either alone or together with a partner (Robinson et al., 2007a, 2007b).

The dyadic (i.e., with a partner) learning group reported greater intentions to perform SSE,

greater importance of SSE, and higher self-efficacy for performing skin exams. The assessment

of SSE performance over the following three months revealed an increase in skin self-

examination practice in both groups, however the dyadic learning was associated with more

frequent SSE. Nevertheless, it is important to point out that the increase in SSE performance was

modest as 45/65 individuals (69%) in the solo learning condition and 23/65 individuals (35%) in

the dyadic learning condition did not check their skin at all. Further, 19/65 individuals (29%)

who learned with their partners checked their skin only once during the follow-up period with

additional 13 patients checking their skin several times, while the solo learners performed even

fewer self-exams (9 and 4, respectively) (Robinson et al., 2007a).

Only three randomized controlled trials related to SSE have been conducted to date. The

most recent one, is a large-scale RCT following 494 participants for 24 months (Robinson et al.,

2014; Robinson et al., 2016). The trial involved patients with a history of early-stage melanoma

(stages 0 to II) as well as their significant others (e.g., spouse, relative, etc.). The study had three

arms with all interventions taking place in the office: a) a face-to-face meeting with an educator,

b) reviewing an educational workbook or c) learning via an electronic interactive education

delivered on a tablet computer, all of which had the goal of increasing knowledge and skills

necessary for SSE. Self-exam knowledge and confidence in performing SSE, i.e., self-efficacy,

were measured immediately after the intervention. The group using the tablet did not differ from

the individuals in the workbook condition in terms of their self-confidence in recognizing

suspicious moles. Further, all groups reported similar levels of self-confidence for accurate

identification of pictures of moles as benign or malignant and in monitoring their own moles.

Individuals in the face-to-face education condition performed significantly better on a skill-based

quiz, followed by the electronic interactive group, who in turn performed significantly better

than the workbook group participants. The electronic and in-person interventions were more

time-efficient (30 minutes) than the workbook (45 minutes). Both the patients and the partners

reported increased confidence in their ability to perform SSE (Robinson, Hultgren, Mallett, &

Turrisi, 2017). Compared to the control group (who received standard care) the patients, who

received any of the 3 interventions reported significantly increased practice of SSE for all body

parts at 4, 12 and 24 months follow-ups and they discovered more new melanomas (Robinson et

al., 2016). Additionally, the authors reported that in the control group all new melanoma cases

were detected first by a physician, while in the intervention group a majority was detected either

by the patient or the partner (Robinson et al., 2016).

The second randomized controlled trial was based on the educational campaign "Check it

out!" and involved 1 356 patients recruited from routine primary care (Lee, Weinstock, & Risica,

2008; Weinstock et al., 2007). Although, these participants were not at higher risk for melanoma

than the general population it is the only RCT to date showing the effectiveness of a large-scale

educational intervention on the performance of skin self-examination. The intervention included

a provision of instructional materials, comprised of cues and aids, a video, and a brief

counselling session, as well as a follow-up phone call from a health educator and tailored

feedback letters. Thorough SSE was performed by more participants at 2, 6, as well as 12 months

in the intervention group than in the control group (55% vs. 35% at 12 months) (Lee et al., 2008;

Weinstock et al., 2007). Interestingly, the analysis of the data from participants who had not

checked their own skin prior to the intervention showed that at each follow-up nearly half of

them examined their skin thoroughly (2 months: 47%, 6 months: 50%, 12 months: 49%) (Lee et

al., 2008).

The third RCT was conducted with 930 males over 50 years of age from Queensland,

Australia (Janda et al., 2010; Janda et al., 2011). Older males were chosen for this study because

they constitute a demographic group with a higher risk for the diagnosis of more advanced

melanoma but lower likelihood of performing SSE compared to women and younger individuals.

The trial randomized the participants into receiving video and print materials on SSE, followed

by two SSE reminder postcards (intervention group) or no follow-up (control group) (Janda et

al., 2010; Janda et al., 2011). Telephone interviews assessed skin self-examination practice at

baseline, 7 and 13 months later. Despite no face-to-face intervention the provision of educational

materials resulted in an increase of SSE behaviours in both groups. At baseline 10% of

participants reported conducing SSE. At 7 months, the proportion of men conducting SSE

increased by 28% in the intervention group compared with 13% in the control group. However,

at 13 months, the prevalence of any skin self-examination was similar in both intervention

groups (83% vs. 80%) (Janda et al., 2010; Janda et al., 2011). The lack of significant differences

between the groups at the end of the study may reflect a potential plateau effect as this study

reported a very high SSE prevalence in this population. It is noteworthy that research from

Australia typically reports higher SSE practice as compared to the rest of the world. This could

be because melanoma is much more common in that population (being "the national cancer")

and the awareness of the skin cancer risk and knowledge about prevention is likely greater than

in North America or Europe given the Australian efforts to raise melanoma awareness over the

past 3 decades. Most importantly, the findings carry an implication that it may be possible to

increase awareness of melanoma and SSE practice in a low-cost manner not requiring the involvement of an expensive and overburdened clinical care team.

Summary and conclusions

Melanoma is recognizable and highly curable at early stages. However, it becomes increasingly difficult to treat as it progresses to more advanced stages. Moreover, melanoma develops with a significant pre-clinical phase making it conducive to early detection (before spreading to other parts of the body). Therefore, it is argued that early detection and treatment are key to reducing melanoma-related mortality (Geller et al., 2007; Weinstock, 2006). Consequently, efforts have been made around the world to facilitate the secondary prevention of the disease. Dermatology associations and clinical guidelines for individuals diagnosed with melanoma have been promoting skin self-examination as a step toward earlier detection and treatment of subsequent tumours melanoma. Cross-sectional and longitudinal studies have identified predictors of SSE, examined means to facilitate SSE as well as provided evidence for the benefits of this health-protective behavioural practice.

The role of the physician in promoting skin self-examination

A multitude of factors appear to be involved in the acquisition of SSE and long-term adherence to SSE recommendations among patients with a history of melanoma. One of the variables, which has received only minimal research attention is the involvement of the patient's physician in promoting this health behaviour.

To date, there are only a few studies examining physician-related variables and skin self-examination. For instance, Robinson and colleagues reported that discussing skin cancer prevention with primary physicians was related to greater patient engagement in SSE (Robinson

et al., 1998). A project involving 200 adults from the general population of Rhode Island

revealed that only 9% performed SSE at least once every few months. However, after controlling

for all other significant predictor variables, individuals who were asked by a health care provider

about examining one's own skin were 3.8 times more likely to report conducting SSE (OR=3.8)

(Weinstock et al., 1999). Similarly, a population-based cross-sectional survey of 3 110

individuals living in Australia, a country with one of the highest incidence of melanoma and

prevalence of SSE, revealed that 18.6% of the participants recalled their primary care physician

suggesting they conduct SSE and 10.8% recalled the physician giving them specific instructions

on how to do it (Aitken et al., 2004). In this study, the practice of SSE has been assessed with

single questions covering at least a full year at a time ("In the past 12 months did you practice

any SSE/whole-body SSE/partial SSE?" and "In the past 3 years did you practice whole body

SSE?") (Aitken et al., 2004). Such operationalization of SSE practice may have contributed to

unusually high reports of SSE, e.g., as a staggering 65% of participants whose physician had

conducted a whole-body skin examination in the previous three years reported checking their

own skin as well. Further, 60% of individuals whose physician had suggested they perform SSE

and 69% of those who had been instructed on how to do it reported conducting SSE (Aitken et

al., 2004). Participants who were encouraged in any of the above two ways were significantly

more likely to report performing SSE within the previous three years, prompting the authors of

the study to conclude that "primary care physicians, either by examining the skin of their patients

or by advising them to examine their skin themselves, may increase the likelihood of SSE in

their patients by as much as 50%" (Aitken et al., 2004).

    A similar research project was conducted by Manne and colleagues (2004) with

individuals at high risk for melanoma, i.e., biological relatives of patients with melanoma. It

assessed whether a physician had ever suggested to the participants to regularly examine their skin and whether the patients remembered being shown how to do it. Forty-five percent of the participants reported being told by their physician to perform SSE but only about half of them (24% of the sample) indicated that they had been shown how to do it. Although the physicians' recommendations were not very common, they were positively associated with SSE practice as participants were much more likely to engage in SSE when they were encouraged to do so (OR=3.8) or shown how to do it (OR=4.3) (Manne et al., 2004). A second project by Manne and colleagues (2006) reported on 229 patients diagnosed with melanoma, who were asked whether a doctor suggested to self-examine their skin and whether a doctor had shown them the best way to do SSE (Manne & Lessin, 2006). Eighty percent of the patients reported that their doctors had recommended SSE but only 46.1% had been shown how to do it. Both physicians' behaviours were associated with greater SSE performance (OR=2.8 and 2.5, respectively) (Manne & Lessin, 2006).

Finally, a pilot clustered-RCT conducted with 20 physicians in private practice in Western France and their 173 patients from the general population showed that physicians may have a significant impact on the patients' melanoma-preventative behaviours and risk self-assessment skills (Rat et al., 2014). In the intervention arm of the study 10 general practitioners identified patients at elevated risk for melanoma with the Self-Assessment Melanoma Risk Score (SAMScore), examined their skin, and counselled them on melanoma, sun protection and SSE using information leaflets. In the control group, 10 general practitioners displayed a poster and the leaflets in their waiting rooms and examined patients' skin at their own discretion. Five months later the participants in the intervention group were more likely to correctly identify their elevated risk of melanoma (71.1% vs. 42.1%), to have performed skin self-exams in the past year

(52.6% vs. 36.8%) and they were less likely to sunbathe (24.7% vs. 40.8%) (Rat et al., 2014). It

is noteworthy that despite the relatively short post-intervention period (5 months) SSE was

assessed for the previous year, which possibly meant a 5-month overlap between the reported 12

months and time since the intervention. Nevertheless, the statistically significant difference

between the groups was also clinically significant.

In sum, while research on physician support for melanoma patients' SSE practice is

scarce, findings to date suggest that patients who have had discussions with their physicians

about checking their own skin for suspicious changes are more likely to practice SSE. Further

investigation into the role of the physician for patient adherence to SSE recommendations is

necessary in order to better understand which specific physician-related factors promote

adherence to medical recommendations of SSE for patients in melanoma after care.

Limitations of the current scholarship on secondary prevention of melanoma through early

detection via skin self-examination among melanoma survivors

Populations under study

Although substantial strides have been made in the past decades in research on the

effectiveness of SSE as well as on predictors of SSE practice among individuals diagnosed with

melanoma, some important limitations are still restricting the conclusions that can be drawn for

secondary prevention of the disease among melanoma survivors. One factor that is limiting

conclusions for this specific and steadily growing population is that a large proportion of the

existing scholarship pertains to SSE among the general population or among individuals at

increased risk but without a previous diagnosis of melanoma. The findings from research

conducted with these groups may not always be directly applicable to melanoma survivors as

previously diagnosed individuals may have a very different experience with this cancer than the

general population. For example, a significant number of melanoma survivors live with the fear

of recurrence, which is likely to impact the likelihood of performing SSE (Atkinson, Noce, Hay,

Rafferty, & Brady, 2013; Noorda et al., 2007). Further, survivors tend to cope with distress by

relying on their physicians' expertise. Indeed, in a study of 483 melanoma patients surveyed

from immediately after the diagnosis up to 10-years post diagnosis, the two most frequently

endorsed ways of coping were "trusting my doctors" and "following the medical advice exactly"

(Zschocke, Augustin, & Muthny, 1996). Thus, it is conceivable that physician recommendations

may have a different impact among cancer survivors than among the general population.

Consequently, due to the scarcity of research with melanoma survivors only tentative

conclusions regarding the role of the physician for SSE practice among melanoma survivors can

be drawn at this time.

The role of the physician for facilitating skin self-examination

Despite a great number of factors identified as predictors of skin self-examination

practice some variables still have not received adequate attention. For instance, based on the

here-presented literature review one can conclude that the role of the physician in promoting the

secondary prevention of melanoma through SSE among melanoma survivors is still largely

unexplored. There are only two studies to date examining the association between physician

recommendations and SSE in this population (Manne & Lessin, 2006; Zschocke et al., 1996).

Yet, the importance of this variable should not be overlooked. It is one of the few potential

predictors of SSE that is modifiable, as many of the other predictors are sociodemographic in

nature and cannot be changed. Among other changeable predictors are cognitive factors such as

SSE-related self-efficacy and knowledge about melanoma and SSE, which could be effectively

addressed by health care professionals, which further highlights the potential importance of the physician's role for the secondary prevention of melanoma (Hay et al., 2006; Mujumdar et al., 2009; Phelan et al., 2003; Robinson et al., 2002; Robinson et al., 1998). However, physicians tend to be occupied with attending to the medical aspects of melanoma treatment and seeing a large number of patients per day. Thus, they may not be able to teach SSE skills or provide patients with detailed information about early signs of melanoma. Research also indicates that interventions carried out by nurses may be very effective (Hay et al., 2006; Oliveria et al., 2004; Phelan et al., 2003). At the same time, merely the physicians' mentioning the need for SSE during a patient's visit is associated with increased SSE practice. Consequently, the role of the physician may be to simply encourage and support the self-examination practice, while the direct teaching or providing educational materials may be accomplished by other healthcare professionals, such as nurses (Aitken et al., 2004; Weinstock et al., 1999).

Research methodology

Operationalization of SSE. One of the major limitations of the past research is the variety of definitions used to operationalize SSE. Based on different criteria used to define what constitutes adequate skin self-examination in different research projects the estimates of the prevalence of SSE among survivors of melanoma vary significantly (Körner et al., 2013; Weinstock et al., 2004), which may also affect the valid assessment of outcomes of interventions aiming to increase effective SSE. Researchers have used different methods to assess melanoma from simple, straight-forward questions to using whole-body diaries for patients to record what they observed during their SSE. Further, the research protocols, which ask questions, sometimes require a simple "yes/no" answer and sometimes provide a scale with different frequencies to choose from (with response items varying from study to study). Additionally, some researchers

define "thorough SSE" by number of body parts examined, while others do not inquire about the thoroughness of the SSE but ask only about whether a participant examined their skin at all. For instance, Rat and colleagues (2014) asked their participants: "In the last 12 months, did you perform a skin self-examination?", without specifying what skin self-examination is (Rat et al., 2014). In contrast, Weinstock and associates (1999) asked their participants whether they looked "specifically and deliberately" at 8 different body areas (arms and face, chest and front of legs, side of body, back of legs, upper back and tops of shoulders, sides of legs and bottoms of feet, middle and lower parts of back, and back of thighs) and the answer was considered affirmative (indicating "thorough SSE") only if the participants chose "always" or "almost always" response options (Weinstock et al., 1999). Such variability in operationalization makes it difficult to compare findings across studies and to conclude if, how many and why melanoma survivors adhere to a regular schedule of whole-body SSE in line with what is recommended by clinical care guidelines the associations of dermatologists suggest.

Research design. The majority of the studies on SSE are cross-sectional or have a short duration with the usual follow-up of adherence to standardized SSE instructions assessed between 3 and 6 months (Berwick, Oliveria, Luo, Headley, & Bolognia, 2000; Oliveria et al., 2004; Robinson et al., 2007b) with a notable exception of one project extending the follow-up to 2 years (Robinson et al., 2014; Robinson et al., 2017; Robinson et al., 2016). Furthermore, different kinds of evidence are needed to demonstrate how effective an intervention is. For instance, naturalistic studies (taking place in unaltered clinical environments) may offer an opportunity to better understand facilitating factors and barriers to implementing SSE interventions and investigate the *effectiveness* of such interventions thereby contributing to establishing external validity of an intervention (Singal, Higgins, & Waljee, 2014). On the other

hand, *efficacy* studies such as RCTs and pre/post designs may allow to establish key predictors of SSE in more controlled environments and inform about the internal validity of the study findings regarding an intervention (Singal et al., 2014). To date, naturalistic effectiveness studies have not been very common. In fact, most studies have been geared toward establishing the efficacy of interventions in somewhat controlled environments. However, even among the efficacy studies, the "gold-standard" of randomly assigning participants to treatment conditions has rarely been reached. Only four RCTs have been reported in the literature on secondary prevention of melanoma. Three of those studies did not involve melanoma survivors but individuals at risk for skin cancer recruited from primary care settings or individuals from the general population. Although informative, this limits the generalizability of the findings to those with a personal history of the disease (Janda et al., 2011; Lee et al., 2008; Weinstock et al., 2007). Longer follow-ups are essential in order to establish whether the intervention effects are long-lasting or last only through the period when the patients are seen frequently by the physicians anyway. In conclusion, longer follow-ups as well as wider range of scientific evidence on the effectiveness and efficacy of interventions aiming to increase SSE among melanoma survivors are needed.

Research objectives of the doctoral dissertation

The main objective of the here-proposed research is to the explore the role of physician support for patients' practice of skin self-examination. More specifically, the first objective is to evaluate whether SSE-specific physician support is a better predictor of SSE than general physician support. To achieve that goal, the psychometric quality of a measure of general support by the physician (i.e., the Health Care Climate Questionnaire) and the measures utility in a population of melanoma patients will be examined. Then, the Physician Support of Skin Self-Examination Scale and the Health Care Climate Questionnaire will be compared in terms of the

strength of their respective associations with SSE. The stronger predictor will be chosen for

subsequent analyses.

The second objective is to evaluate patients' self-efficacy specific to SSE. First, the

baseline level of SSE self-efficacy will be established at study enrolment. Second, best-practice

clinical care will be modeled by providing a brief educational intervention focusing on the

detection of early signs of melanoma. The patients' level of self-efficacy will be assessed

immediately after the intervention as well as 3 and 12 months later. Finally, the relationship

between physician support and SSE self-efficacy will be examined.

The third objective is to examine the relationship between physician support and SSE

behavioural practice. To better understand their potential positive association, a mediational

pathway will be tested whereby the level of patients' self-efficacy is proposed to explain the

association between physician support and SSE practice.

Chapter 2

Validation of the English and French Versions of the Brief Health Care Climate

Questionnaire (HCCQ)

Zofia Czajkowska, Hui Wang, Nathan Hall, Maida Sewitch and Annett Körner

Author Note

Zofia Czajkowska, Hui Wang, Nathan Hall, and Annett Körner - Department of Educational and Counselling Psychology, McGill University; Maida Sewitch – Department of Epidemiology, McGill University Health Centre

Correspondence concerning this article should be addressed to Zofia Czajkowska, Department of Educational and Counselling Psychology, Montreal, QC, H3A 1Y2.
E-mail: zofia.czajkowska@mail.mcgill.ca

Abstract

Patient autonomy is a central value in medicine and critical component of adherence to medical advice. This paper reports on a validation of the 6-item version of the Health Care Climate Questionnaire (HCCQ), a measure of autonomy support in health care settings, in a sample of 242 melanoma patients. The HCCQ showed excellent internal consistency (α=.91), structural validity (TLI = .99; CFI = .99; RMSEA = .06, 90% CI (Van Durme et al., 2000); SRMR = .02; χ^2 (8, N = 235) = 13.99, p =.08), and construct validity (85.71% of hypothesized correlations with other measures confirmed). Acceptable 3-month test-retest reliability was observed (r= .55, p< .001; ICC (A,1) = .54, p<.001). The French version was found equivalent to the English version.

Keywords: Health Care Climate Questionnaire; HCCQ; validation; HCCQ version française; HCCQ brief version; HCCQ short version; patient autonomy; melanoma; skin cancer

Introduction

The purpose of the current paper is to validate a Health Care Climate Questionnaire (HCCQ) – a unique measure of the patient perspective concerning their autonomy in medical settings. Patient autonomy is a central value in Western medicine (Beauchamp & Childress, 2009; Varelius, 2006) and one of the fundamental principles of the Charter on Medical Professionalism (Teplick et al., 2006). Accordingly, this principle states that *"physicians must have respect for patient autonomy… be honest with their patients and empower them to make informed decisions about their treatment"* (Teplick et al., 2006; p. 1). This recent official adoption of patient autonomy as a part of the physicians' charter thus indicates that health care practitioners are now responsible for promoting both autonomy and well-being in their patients (Beauchamp & Childress, 2009; Ng et al., 2012).

According to Self-Determination Theory, patients' sense of autonomy represents a critical component of their motivational profile (Patrick & Williams, 2012; Ryan & Deci, 2006; Ryan, Patrick, Deci, & Williams, 2008; Williams, Deci, & Ryan, 1998; Williams, Frankel, Campbell, & Deci, 2000; Williams, Freedman, et al., 1998; Williams et al., 1996). In health care settings, autonomous motivation is of particular importance concerning patient adherence to medical advice, treatment, and disease prevention. According to Sox, 2002, *"the center of patient care is not in the physician's office or the hospital. It is where people live their lives, in the home and the workplace. There, patients make the daily choices that determine their health"* (p. 243). Unfortunately, the choices made by patients do not always contribute to better health outcomes. For example, non-adherence to medication ranges from 25% to 50% and is associated with more hospital admissions and medical complications (Alvarez Payero et al., 2014; Beck, Emery, & Greenberg, 1985; Claxton, Cramer, & Pierce, 2001; Haynes, McDonald, Garg, & Montague, 2002;

Nieuwlaat et al., 2014; Sokol, McGuigan, Verbrugge, & Epstein, 2005). In addition to health

problems experienced by the patients, there are significant financial costs associated with greater

hospitalization, medical tests, and treatments due to patient non-compliance (Berg, Dischler,

Wagner, Raia, & Palmer-Shevlin, 1993; Iuga & McGuire, 2014; Roebuck, Liberman, Gemmill-

Toyama, & Brennan, 2011; Sokol et al., 2005). Moreover, the current methods of increasing

adherence tend to complex in nature and largely ineffective (Haynes et al., 2002; McDonald, Garg,

& Haynes, 2002; Nieuwlaat et al., 2014).

      Why do patients not follow medical advice? From the perspective of the patient, the

seemingly irrational act of non-compliance may be perceived as having a rational basis (e.g.,

unfavourable cost-benefit analysis or lacking sufficiently persuasive reasons to comply; DiMatteo

et al., 2007; Donovan and Blake, 1992). Moreover, given that patient beliefs concerning their

personal circumstances, prior knowledge, and medical options are salient antecedents of their

subsequent health-related decision-making, their personal beliefs concerning medical issues and

physician support are indeed worthy of empirical study (Donovan & Blake, 1992; Vermeire,

Hearnshaw, Van Royen, & Denekens, 2001). Patient involvement in the treatment process and the

relationship between the patient and healthcare professionals are among the core element of

patient-centered care internationally (Kitson, Marshall, Bassett, & Zeitz, 2013). Further, an

autonomy-supportive climate of mutual understanding, trust, and shared decision-making between

the patient and the physician has been found to be conducive to discussing patients' concerns,

increasing adherence, and facilitating patient participation, each of which correspond to various

positive outcomes (Greene & Hibbard, 2012; Hibbard & Greene, 2013).

      For instance, greater communication between the patient and the health care team has been

found to improve not only treatment adherence but also patient satisfaction (Burnier, 2000;

Donovan, 1995; Fuertes et al., 2007; Ha & Longnecker, 2010; Hillen, de Haes, & Smets, 2011). Additionally, more effective provider-patient communication is associated with greater work satisfaction, less work-related stress, and lower burnout for medical professionals that, in turn, can facilitate patient adherence and satisfaction with care (DiMatteo et al., 1993; Ha & Longnecker, 2010; Pepper, Carpenter, & DeVellis, 2012; Stavropoulou, 2011; Zolnierek & DiMatteo, 2009). With respect to the qualities of effective communication, findings suggest that shared decision-making, presenting options, addressing patients' concerns, and mutual trust are critical to patient-physician relationships and health outcomes (Ha & Longnecker, 2010; Hillen et al., 2011; Stavropoulou, 2011). It is these key aspects of communication between a health care provider and a patient that are captured by the Health Care Climate Questionnaire (HCCQ) developed by Williams et al. (2000) in which patients' perceptions concerning autonomy-supportive nature of the health care climate are specifically assessed.

The HCCQ has been used in research for over 20 years to measure patients' perceptions concerning the extent of autonomy support provided by their health care providers (Fortier, Sweet, O'Sullivan, & Williams, 2007; Kasser & Ryan, 1999; Williams, Cox, Kouides, & Deci, 1999; Williams, Deci, et al., 1998; Williams, Freedman, et al., 1998; Williams, Gagne, Ryan, & Deci, 2002; Williams et al., 1996; Williams et al., 2006). According to Williams et al. (2000), autonomy support in health care settings *"refers to providers' interacting with patients by taking full account of their perspectives, affording choice, offering information, encouraging self-initiation, providing a rationale for recommended actions, and accepting the patients' decisions"* (p. 81). The HCCQ was designed specifically to assess these specific aspects of autonomy support in health care environments. It was developed based on prior work with similar questionnaires in non-health care settings (Williams et al., 1996), and can be adapted for use with various medical professionals

including physicians, nurses, and dieticians (Williams et al., 1998b). However, given limited

published research to date on the empirical validation of the HCCQ, the purpose of this study was

to assess the validity and reliability of this self-report measure. Given that researchers and

clinicians alike typically prefer less intrusive measures that perform optimally, the short 6-item

version of the original 15-item scale was examined with respect to internal consistency, structural

and construct validity, test-retest reliability, as well as descriptive and item-specific statistics.

Scale validation was conducted in a hospital-based sample of patients diagnosed with

melanoma skin cancer. This population was selected due to clinical guidelines recommending

long-term adherence to a skin self-examination regimen for melanoma survivors (Coit et al., 2009),

thereby affording a sufficiently intensive examination of patient autonomy in the context of

medical adherence. In addition to scale validation, the second study objective was to examine

English-French language equivalency in terms of mean level differences as well as contrasting

internal consistency, structural validity, and item/scale descriptives between the English and

French samples. French was chosen as a second language due to the measure having previously

been employed in French samples despite no published scale validation for the French version

(Fortier et al., 2007).

Method

Participants

The study sample consisted of patients diagnosed with melanoma skin cancer treated at

two major teaching hospitals in Montreal, Canada. Eligibility criteria included the ability to read

either English or French, being at least 18 years of age, and having a medically confirmed

diagnosis of melanoma. Fifteen percent were diagnosed with melanoma in situ (stage 0), 48.7%

with stage I, 18.7% with stage II, 6.2% with stage III, and 3.6% with stage IV melanoma.

Materials

      Health Care Climate Questionnaire. The Health Care Climate Questionnaire (HCCQ)

was utilized to assess the degree to which the participants perceived their physicians as supportive

of their autonomy as opposed to controlling in nature (Williams et al., 1996). Sample items include

"I feel that my doctor has provided me choices and options," "My doctor tries to understand how

I see things before suggesting a new way to do things," and "My doctor encourages me to ask

questions." Each item was rated on a 7-point Likert scale ranging from 1 (*strongly disagree*) to 7

(*strongly agree*). The language of the scale is devoid of jargon, double negative statements, and

advanced vocabulary to optimize accessibility for individuals across education levels. Similar to

the original 15-item scale having excellent internal consistency (Cronbach's α = .95) and a 1-factor

structure (Williams et al., 1996), high internal consistency (Cronbach's α = .96) and a 1-factor

structure were also obtained in the current sample.

      Comprised of items from the original 15-item version, the shorter 6-item scale includes

items 1, 2, 4, 7, 10, and 14 (Self-Determination Theory, 2017). Similar short versions with 4

(Williams et al., 1999; Williams, Rodin, Ryan, Grolnick, & Deci, 1998), 5 (Williams et al., 1996,

1998b, 2002), and 7 items (Kasser and Ryan, 1999) have previously demonstrated acceptable to

excellent internal consistency (.72 $\leq$ Cronbach's $\alpha \leq$ .96) and reflected a 1-factor structure (Fortier

et al., 2007; Kasser and Ryan, 1999; Williams, 1996, 1998b, 1998c, 1999, 2002, 2006). For the

purposes of this study, the 6-item version was administered following from a recommendation of

this version by the scale authors (Self-Determination Theory, 2017). The 15-item version was

additionally administered to examine correlations between the full and 6-item scale versions.

Other measures. Socio-demographic data (age, gender, years of education, etc.) and need for additional services (e.g., to spend more time with the physician) were assessed via a self-report survey. Time since diagnosis and cancer stage were additionally collected from patients' medical files and hospital tumour registries. The *Physician Support of Skin Self-Examination (SSE) Scale* assessed the patients' perspective of their doctors' encouragement of skin self-examination (Coroiu, Moran, Garland, & Körner, 2017) and patients' self-efficacy for SSE was assessed using *Skin Self-Examination Self-Efficacy Scale* (Karapetian et al., 2016). The Skin Self-Examination was assessed with 5 items inquiring about whether different body parts have been examined by a participant. The *Skin Cancer Index* was used to measure patients' worries specific to skin cancer (Matthews, Rhee, Neuburg, Burzynski, & Nattinger, 2006; Rhee et al., 2007), while the *Patient Health Questionnaire-4* used to assess psychological distress with respect to depressive and anxiety symptoms (Kroenke, Spitzer, Williams, & Lowe, 2010).

Procedure

Design. Ethics approval was obtained from the university's faculty of medicine research ethics board. This specific study was conducted at two teaching hospitals as part of a larger, longitudinal project examining how psychosocial variables correspond with adherence to medical advice during melanoma follow-up clinical care. Further procedural details are outlined in a published study protocol (Körner et al., 2013).

Translation. There exists no official validated French version of the HCCQ despite its previous use in English-French bilingual settings (e.g., Fortier et al., 2007). Consequently, a professional translator was employed to translate the HCCQ as per a cross-cultural translation technique (Banville, Desrosiers, & Genet-Volet, 2000). First, a professional translator from Québec, Canada (study location) fluent in both English and French translated the HCCQ from the

original English into French. Second, a bilingual individual without access to the original version back-translated the measure into English. Third, the original and back-translated versions were compared and consensus on the final version was reached between both translators. The 7-item response format was retained from the English version (1 = *fortement en désaccord*, 3 = *neuter*, 7 = *fortement en accord*). The translated questionnaire items are presented in Table 1.

Analyses. The validation analyses were principally conducted using baseline data (Time 1) from the longitudinal project to afford the greatest number of participants ($N = 242$). To evaluate test-retest reliability, data from Time 2 (6-month lag, $N = 109$) and Time 3 (9-month lag, $N = 112$) data were additionally assessed. First calculated were item means, standard deviations, Cronbach's alpha if item deleted, inter-item correlations, corrected item-total correlations, and factor loadings, as well as the scale mean and standard deviation. Second, the correlation with the full scale (15-item version) was calculated, followed by Cronbach's alpha and a confirmatory factor analysis (CFA) for the 6-item scale. Construct validity was evaluated by comparing the HCCQ to similar and dissimilar constructs using Pearson's r and point biserial correlations. Reproducibility of the HCCQ scores (test-retest reliability) was assessed by correlating Time 2 and Time 3 data using the intraclass correlation coefficient (ICC). Additionally, floor and ceiling effects were investigated.

Equivalency between the English and French versions was examined by a) correlating language with the HCCQ score, b) comparing group means, c) comparing CFA fit and factor loadings between the English and French subsamples, d) comparing overall Cronbach's alphas and item-corrected Cronbach's alphas of the English and French groups, and e) comparing item-level analytics (inter-item correlations, item-total correlations, item means). Confirmatory factor analyses were conducted using Mplus statistical software. version 7.0. (Muthén & Muthén,

released 2012), with the remaining analyses conducted using Predictive Analysis Software (PASW version 18; SPSS Inc., 2009).

Results

Descriptive and item analyses. Item means were similar in magnitude ranging from 4.74 to 5.64 (SD = 1.44-1.68) with an average item mean of 5.29 (average mean across all individual item means). Similarly, the means for the entire scale (regardless of single items deleted) remained within a range of 1 point (from 26.09 to 26.98). The inter-item correlations ranged from .55 to .75 ($p < .001$ for all). Further, corrected item-total correlations were high and comparable across items (ranging from .68 to .82) as were the Cronbach's alphas if item deleted (ranging from .88 to .90). The short, 6-item version of the questionnaire correlated very highly with the original, 15-item version (r = .95, $p < .001$). Additionally, all items showed excellent factor loadings (for more details on the structural validity see the next section) (Tabachnick & Fidell, 2013). Additional details regarding the analyses described above can be found in Table 2.

Internal consistency and structural validity. Cronbach's alpha was high (α = .91) indicating excellent internal consistency (Streiner, 2003; Terwee et al., 2007). Further, as the HCCQ is considered a 1-factor scale (Wiliams, 1996, 1998b), a confirmatory factory analysis (CFA) was conducted to corroborate previous findings. Two hundred and thirty-five participants' data was used in this analysis allowing for sufficient power to detect a model fit (Terwee et al., 2007). A CFA with maximum likelihood estimation showed an excellent fit following Hu and Bentler's (Hu & Bentler, 1999) as well as Kline's (Kline, 2013) criteria (TLI = .99; CFI = .99; RMSEA = .06, 90% CI; SRMR = .02; χ^2 (8, N = 235) = 13.99, p = .08). The factor loadings ranged from .74 to .90.

Construct validity. As per recommendations by Terwee and colleagues (2007), construct validity was established by testing hypotheses on how the HCCQ should correspond to similar and dissimilar constructs through correlations, pertinent single items as well as sociodemographic and medical data (see *Measures*). Twelve of 14 hypotheses (listed in Table 3) were supported (85.71%) providing evidence for the construct validity of HCCQ (for more details see Table 3; Terwee et al., 2007). Two hypotheses were not supported. First, the one involving the Emotional subscale of the SCI in that a moderate correlation was expected but no significant correlation was observed. Thus, whereas general sense of distress (PHQ-4) did correspond negatively with the HCCQ, specific symptoms of distress as assessed by the emotional subscale of SCI (e.g., embarrassment about cancer and worries) did not relate to perceived autonomy as measured by the HCCQ. Second, a small to moderate correlation was expected between HCCQ and the Skin Self-Examination, however, the correlation was not significant.

Reproducibility. Test-retest reliability was established by correlating Time 2 and Time 3 data (gathered 3 months apart) and computing the intraclass correlation agreement (ICC). The data from T2 and T3 showed a strong correlation (J. Cohen, 1988), which is notable given the time lag and the possibility of some patients having consulted different physicians during this period ($r =$ .55, $p < .001$). Additionally, the intraclass correlation coefficient (ICC) was calculated to assess test-retest reliability (Weir, 2005). Unlike Pearson's r, the ICC accounts for both consistency of performances from test to retest (within-subject change), as well as change in average performance of participants as a group over time, i.e., systematic change in the mean (Vaz, Falkmer, Passmore, Parsons, & Andreou, 2013). Using a two-way random effects model (McGraw & Wong, 1996), ICC values showed reliability to be adequate (ICC (A,1) = .54, $p < .001$ - Equivalent to ICC (2, 1) in Shrout and Fleiss's notation, 1979) (Shrout & Fleiss, 1979).

Floor and ceiling effects. The lowest possible score of 6 was obtained by 1% of the sample and the highest possible score of 42 was obtained by 10.8% of the sample. Thus, based on McHorney and Tarlov's (1995) criteria, no floor or ceiling effects were detected (McHorney & Tarlov, 1995).

English-French equivalency. We further examined differences between the English and French versions of the HCCQ concerning group means, dimensionality, and internal consistency. First, the correlation between the HCCQ score and language was not significant ($r_{pb} = $ -.03, $p = $ .67). Second, HCCQ scale means were very similar between the English and French subsamples ($M_{En} = 31.92$, $SD = 7.78$; vs. $M_{Fr} = 31.48$, $SD = 7.51$) as indicated by a nonsignificant t-test ($t(218) = .43$, $p = .67$). Third, average item means (average across all individual item means) were only .07 apart with each item mean falling into similar ranges for each subgroup ($M_{En} = 5.32$, range: 4.72 - 5.79, $SD = 1.42 - 1.75$; vs. $M_{Fr} = 5.25$, range: 4.76 - 5.59, $SD = 1.42 - 1.62$). Similarly, inter-item correlations for the subgroups showed comparable ranges (English: .53 - .76; vs. French: .54 - .79). Lastly, corrected item-total correlations were high and comparable across the items (English: .67 - .81; vs. French: .69 - .83).

Confirmatory factor analyses were conducted for the English and the French subgroups separately using a maximum likelihood estimation and showed very good model fits (see Hu and Bentler, 1999; Kline, 2013): English: ($n = 119$): TLI = .96; CFI = .97; RMSEA = .11, 90% CI [.05, .17]; SRMR = .03; χ^2 (9, $N = 119$) = 22.12, $p < .01$; vs. French: ($n = 115$): TLI = .99; CFI = .996; RMSEA = .04, CI [.00, .12]; SRMR = .02; χ^2 (8, $N = 115$) = 9.62, $p = .29$. Data from the French subgroup indicated slightly better model fit than for the English subgroup. The factor loadings in the English subsample ranged from .69 to .87, and in the French subsample ranged from .75 to .92. Finally, observed Cronbach's alphas for the two subscales were excellent (English: $\alpha = .91$; vs.

French: α = .90) and remained in similar ranges when an item was deleted (English: .89 ≤ α ≤ .91; vs. French: .87 ≤ α ≤ .90). Overall, it can be concluded that the scale performed equally well in English and French, and thus can be considered valid for use in these two languages.

Discussion and Conclusion

Discussion. The Health Care Climate Questionnaire was first introduced over 20 years ago (Williams et al., 1996) and has been used in numerous studies (Fortier et al., 2007; Kasser & Ryan, 1999; Williams et al., 1999; Williams, Deci, et al., 1998; Williams, Freedman, et al., 1998; Williams et al., 2002; Williams et al., 1996; Williams et al., 2006). Despite its popularity, however, the measure has not been formally empirically examined as to its reliability and validity. First, there is little by way of detailed psychometric information on the 6-item version of the HCCQ, and only limited data on other short versions with four (Williams et al., 1999) (Williams et al., 1998c, 1999), five (Williams et al., 1996, 1998b, 2002), and seven items (Kasser & Ryan, 1999). Accordingly, the present validation analyses of the 6-item official (Self-Determination Theory web page: Health Care Climate Questionnaire) brief HCCQ were conducted to address this research gap.

Second, whereas the scale has been used in French, there is presently no published information as to its psychometric properties. Thus, not only is a valid French version necessary for conducting research using the HCCQ with Francophone participants, one must evaluate the correspondence between the English and French versions to be able to directly compare data from French and English studies using this measure. Consequently, we translated the HCCQ and evaluated the reliability and validity of the scale in both languages in samples of English- and French-speaking melanoma patients.

Overall, the 6-item HCCQ demonstrated excellent validity and reliability with respect to internal consistency, structural validity, and construct validity. Additionally, acceptable three-month test-retest reliability was observed and floor or ceiling effects were not detected. Further, the comparison of French and English versions in terms of scale means, structural validity, and internal consistency did not reveal significant differences between the two subsamples indicating equivalence of performance in these two languages.

Nevertheless, specific limitations warrant discussion. First, the data in the present analyses are based on a sample of modest size, that although is adequate (minimum10 participants per item, minimum 100 data points over all for the CFAs; Terwee et al., 2007), did not significantly exceed standard benchmarks (115 in the French subsample, 119 in the English subsample). Second, in our examination of construct validity it was not possible to compare the HCCQ to another gold standard measure of the "health care climate" or "health care provider support of patient autonomy" as no such measures exist. Thus, the measures used to establish construct validity were not redundant but instead represented close approximations to the construct proposed to be captured by the HCCQ.

Third, whereas it is recommended that reliability testing of health status questionnaires be conducted one or two weeks apart – long enough for the participants to forget scale items but short enough for no significant change to occur (Terwee et al., 2007) – the present lag was three months with some patients likely having consulted different physicians between Time 2 and Time 3. Given the substantial time lag, we consider the strong correlation and the adequate ICC as indicative of robust test-retest reliability. Given these limitations, future research to validate the HCCQ in different populations with larger samples and shorter retest lags are encouraged. Finally, as the

analyses were conducted for patients specifically diagnosed with melanoma skin cancer, the utility of the HCCQ in other populations warrants investigation.

Conclusion. The brief, 6-item version of the Health Care Climate Questionnaire is a reliable and valid measure of perceived physician support of autonomy among patients diagnosed with melanoma, as administered in both English and French languages.

Practice implications. To our knowledge, the use of HCCQ in clinical practice has not been reported in the existing literature and we hope that validating the measure will open doors to its potential use outside of research. The HCCQ-6 is recommended as a reliable and valid measure for use in future research and clinical practice to assess patients' perceived autonomy in both Anglophone and Francophone populations.

Table 1. Items of the HCCQ in English and French (6-item version items are italicized).

1. *I feel that my doctor has provided me choices and options.* *Je sens que mon médecin m'a informé de mes choix et de mes options.*
2. *I feel understood by my doctor.* *Je me sens compris par mon médecin.*
3. I am able to be open with my doctor at our meetings. Lors de nos entretiens, je suis en mesure de parler ouvertement avec mon médecin.
4. *My doctor conveys confidence in my ability to make changes.* *Mon médecin a confiance en mon habileté à apporter des changements.*
5. I feel that my doctor accepts me. Je sens que mon médecin m'accepte.
6. My doctor really understands about my condition and what I need to do. Mon médecin s'est assuré que j'ai pleinement compris mon état et ce que je dois faire.
7. *My doctor encourages me to ask questions.* *Mon médecin m'encourage à poser des questions.*
8. I feel a lot of trust in my doctor. J'ai très confiance en mon médecin.
9. My doctor answers my questions fully and carefully. Mon médecin répond complètement et soigneusement à mes questions.
10. *My doctor listens to how I would like to do things.* *Mon médecin prend en compte comment je désire faire les choses.*
11. My doctor handles people's emotions very well. Mon médecin gère très bien les émotions des autres.
12. I feel that my doctor cares about me as a person. Je sens que mon médecin s'intéresse à moi en tant que personne.
13. I don't feel very good about the way my doctor talks to me. Je ne me sens pas très à l'aise à propos de la façon dont mon médecin me parle.
14. *My doctor tries to understand how I see things before suggesting a new way to do things.* *Mon médecin tente de comprendre mon point de vue avant de suggérer une nouvelle façon de faire les choses.*
15. I feel able to share my feelings with my doctor. Je me sens à l'aise de partager mes sentiments avec mon médecin.

Table 2. Health Care Climate Questionnaire - Item analyses based on the total sample ($N = 222$)

HCCQ at T1	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Total
Mean	5.52	5.64	5.18	5.38	5.27	4.74	31.73
Standard Deviation	1.55	1.44	1.46	1.68	1.56	1.51	7.63
Cronbach α if item deleted	.89	.89	.90	.89	.88	.90	-
Scale *M* if item deleted	26.21	26.09	26.55	26.35	26.46	26.98	-
Corrected ITC[a]	.74	.78	.72	.74	.82	.68	-
Factor loadings	.77	.81	.79	.80	.90	.74	-

a. ITC – Item Total Correlation

Table 3. Correlations between HCCQ-6 and other variables

Correlation hypotheses	Measure	Pearson's r / Point biserial correlation[a]	Mean (SD)	α[b]	Possible range of scores	Actual range of scores	Hypothesis confirmed?
Moderate to large correlation[d]							
	Physician Support of SSE	.46*** [c]	9.51 (6.77)	.94	0-18	0-18	Yes
	Self-efficacy	.31*** [c]	7.41 (2.93)	.74	0-15	0-15	Yes
Small to moderate correlation[d]							
	Service need: "Do you need more time with the physician involved with your melanoma care?"	-.24*** [c]	.31 (.47)	n/a	0-1	0-1	Yes
	SCI: Emotional Subscale	-.06 [ns]	19.98 (7.93)	.90	7-35	7-35	No
	PHQ-4: Distress	-.23*** [c]	2.69 (3.12)	.85	0-12	0-12	Yes
	Skin Self-Examination	.06 [ns]	14.03 (5.64)	.89	0-25	0-25	No
No correlation[d]							
	SCI: Appearance Subscale	.06 [ns]	12.15 (3.56)	.92	3-15	3-15	Yes
	SCI: Social Subscale	-.02 [ns]	21.27 (3.77)	.77	5-25	6-25	Yes
	Language: English / French[a]	-.03 [ns]	n/a	n/a	n/a	n/a	Yes
	Gender[a]	.01 [ns]	n/a	n/a	n/a	n/a	Yes
	Age	.09 [ns]	59.48 (13.84)	n/a	n/a	26-92	Yes
	Education (in years)	-.04 [ns]	14.78 (3.5)	n/a	n/a	5-26	Yes
	Time since diagnosis (in months)	.05 [ns]	27.88 (50.61)	n/a	n/a	.23-326.23	Yes
	Stage of cancer	.06 [ns]	n/a	n/a	0-4	0-4	Yes

***$p \leq .001$; ns – not significant; n/a – not applicable

a. Point biserial correlation was performed for the dichotomous variables.

b. Cronbach's alpha (α)

c. Significant after applying Bonferroni adjustment for multiple comparisons requiring $p < .004$

d. Magnitude of a correlation is based on Cohen's (1988) criteria.

Linking chapter 2 and chapter 3

Chapter two reports on the validation of the Health Care Climate Questionnaire (Williams, Freedman, et al., 1998; Williams et al., 1996) in a Canadian sample of individuals diagnosed with melanoma. It is a measure of patients' perceptions concerning the autonomy-supportive nature of the health care climate. More specifically, the perceived support by the treating physician is assessed by asking patients about, e.g., feeling understood, accepted, being encouraged to take active role in managing one's health, trusting the doctor, etc. Despite the measure's wide use for over twenty years no explicit validation study had been published. Several brief versions have been utilized. One of them, the 6-item version of the HCCQ, has been endorsed by the original authors of the scale. However, no psychometric validation of this HCCQ version were available prior to the here presented work. In our analyses, the 6-item version of the HCCQ showed excellent internal consistency, structural and construct validity as well as an acceptable 3-month test-retest reliability. Moreover, the whole questionnaire (15 items) was translated into French. The French 6-item HCCQ showed psychometric properties equivalent to those of its English counterpart. Thus, given their psychometric characteristics both abbreviated versions can be recommended to be used in melanoma survivors and similar populations.

Despite its psychometric quality, the HCCQ did not prove to be useful for the purposes of predicting our main variable of interest: skin self-examination (SSE). The current data do not allow to determine whether general support by one's physician is unrelated to self-exam behaviours or if the non-relationship is due to the way physician support is defined and assessed with the 6-item HCCQ. However, given that HCCQ and SSE behaviour did not correlate significantly, this measure of general physician support was excluded from the subsequent analysis. The second measure of physician support, which assesses support specific to skin self-exam behaviours was

used for the subsequent studies included in this dissertation. The Physician Support of SSE Scale (Coroiu et al., 2017) assesses the patient's perspective of the physician's support specific to SSE by asking, for example, whether the doctor recommended SSE, showed how to do it, inquired about the patient's SSE practice or pointed out certain skin spots to pay particular attention to during skin self-exams.

In the following chapter, the Physician Support of SSE scale is used to predict the level of SSE-specific self-efficacy. Previous research has shown that self-efficacy is a predictor of SSE, therefore it is important to understand its potential change over time and what fosters SSE self-efficacy (Auster et al., 2013; Kasparian et al., 2010; McLoone et al., 2013; Mujumdar et al., 2009). Chapter 3 reports on SSE self-efficacy up to one year after receiving an educational intervention on early signs of melanoma and SSE, which was designed to model best-practice care according to guidelines for melanoma follow-up care (National Comprehensive Cancer Network, 2018).

Chapter 3

The role of patient education and physician support in self-efficacy for skin self-examination among patients with melanoma

Zofia Czajkowska, Nathan Hall, Maida Sewitch, Beatrice Wang and Annett Körner

Author Note

Zofia Czajkowska, Nathan Hall, and Annett Körner - Department of Educational and Counselling Psychology, McGill University; Maida Sewitch – Department of Epidemiology, McGill University Health Centre, Beatrice Wang – Melanoma Clinic at McGill University Health Centre

Correspondence concerning this article should be addressed to Zofia Czajkowska, Department of Educational and Counselling Psychology, Montreal, QC, H3A 1Y2.
E-mail: zofia.czajkowska@mail.mcgill.ca

Abstract

Objective: This project aims to elucidate the relationships between skin self-examination (SSE), perceived physician support of SSE, and self-efficacy for SSE among melanoma patients.

Methods: A longitudinal study of patients diagnosed with melanoma was conducted over the span of 18 months. Participants filled out questionnaires at four assessment points and participated in an SSE education about the early signs of melanoma.

Results: Among the 242 patients enrolled, the level of self-efficacy for SSE was 23% higher immediately after the educational intervention ($p < .001$) and the increase was retained three months ($p < .001$) and twelve months later ($p < .001$). Additionally, a one-way repeated measures ANOVA revealed that the perceived physician support of SSE positively corresponded to the level of patient self-efficacy with higher patient-reported physician support being related to higher self-efficacy ($p = .001$).

Conclusion: Patient education and perceived physician support of SSE are positively associated with patients' level of self-efficacy.

Practice implications: Physicians caring for melanoma survivors should be aware that, both SSE education and patients' perception of high physician support of SSE may be associated with higher self-efficacy for checking one's own skin for signs of cancer recurrence.

Keywords: patient education; self-efficacy; physician support; melanoma; skin self-examination (SSE); skin cancer

Introduction

The role of self-efficacy in health behaviours

Self-efficacy has been defined as "people's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances" (p. 391) (Bandura, 1986) and it has been consistently linked with desired behaviours (Bandura, 1997). Although the construct is primarily cognitive in nature by being "concerned not with the skills one has but with judgments of what one can do with whatever skills" (p. 391) (Bandura, 1986) a plethora of research confirms the potential of self-efficacy to predict positive health behaviours ranging from dieting and smoking cessation to cancer prevention (Bandura, 1997; Graves, 2003; Holden, 1992). It can predict both the uptake and the maintenance of health behaviours (Ashford, Edmunds, & French, 2010; Coups et al., 2016), which could be crucial for patients' health and longevity, as in the case of cancer prevention and detection behaviours. For instance, self-efficacy positively predicts intention for sun protection as well as sun-protective behaviours above and beyond habit (Jackson & Aiken, 2000; Mahler, Kulik, Gibbons, Gerrard, & Harrell, 2003). Further, skin self-examination (SSE) practice is much higher among the survivors of melanoma whose self-efficacy for this behaviour is high (OR 14.4) (Mujumdar et al., 2009). Similarly, self-efficacy for breast self-examination predicts both the intention to engage in and the practice of self-exams (Luszczynska & Schwarzer, 2003; S. M. Miller, Shoda, & Hurley, 1996). Lower self-efficacy for managing pain and cancer symptoms predicts greater pain and fatigue, more difficulty in adjusting to cancer, symptoms of depression, anxiety**,** and lower quality of life in addition to worse physical functioning among patients with lung cancer (Porter, Keefe, Garst, McBride, & Baucom, 2008). Not surprisingly then, interventions that aim to increase self-efficacy also typically result in a better

adjustment to cancer including an improved mood and higher quality of life (Cunningham, Lockwood, & Cunningham, 1991; Lev, 1997).

Why does self-efficacy matter for patients with melanoma?

Melanoma represents a prototypical malignancy, in which continuous engagement in tumour-detecting behaviours can lead to an earlier diagnosis and treatment (Manganoni et al., 2007; Talaganis et al., 2014). Melanoma survivors are at an increased lifelong risk for developing new primary tumours and recurrences, with subsequent melanomas affecting up to 11% of patients (Doubrovsky & Menzies, 2003; Ferrone, Ben Porat, Panageas, Berwick, Halpern, Patel, & al., 2005; Kang et al., 1992; Manganoni et al., 2007). Thus, secondary prevention through early detection is particularly important for these individuals (Doubrovsky & Menzies, 2003; Jones et al., 2013). Among skin cancer survivors, medical checkups and regular SSE are recommended by clinical guidelines as a part of melanoma follow-up care (Coit et al., 2009). Clinical skin exams for patients with suspicious skin lesions are crucial as the physicians may be able to detect melanomas at earlier stages than patients would, when the tumours are more amenable to treatment (Carli et al., 2003; Epstein et al., 1999; Schwartz et al., 2002). However, clinical exams are increasingly less likely to include an examination of the entire body of the patient and thus miss up to 1 in 3 melanomas (Aldridge et al., 2013). In contrast, checking one's own skin for changes can increase the likelihood that an individual will consult a physician before the tumour has developed into an advanced stage (Carli et al., 2003; Titus, 2013). Thus, the practice of skin self-examination (SSE) represents an important step toward earlier diagnosis and treatment, and could contribute to a reduction in mortality among melanoma survivors (Berwick et al., 1996; Geller et al., 2006; Titus, 2013). Like many health behaviours, SSE practice following the clinical recommendations may be more likely if patients feel confident

about the capacity to conduct a skin self-exam (Auster et al., 2013; Hay et al., 2006; Kasparian et al., 2010; Mujumdar et al., 2009). Fortunately, self-efficacy specific to SSE can be improved through patient education (Hay et al., 2006; McLoone et al., 2013; Oliveria et al., 2004; Robinson, Turrisi, Mallett, Stapleton, & Pion, 2010; Robinson et al., 2007a).

The importance of medical support

Learning to conduct a skin self-exam is not easy. In order to maximize the likelihood of detecting a potential melanoma, one must check the skin of the entire body including places that are difficult to see such as the upper back, top of the head and soles of the feet; which require**s** some physical agility and the use of a mirror or help from a partner (American Academy of Dermatology, 2018b). Furthermore, to recognize a mole as a potential melanoma, as opposed to a regular nevus, one must know the signs and carefully examine the nevi for asymmetry, border, colour, diameter as well as evolution (American Academy of Dermatology, 2018e). Physicians or nurses, who are knowledgeable about the risk for developing subsequent melanomas and the importance of SSE for early prevention, are in a critical position to impart that knowledge to their patients (Oliveria et al., 2004). Dermatology experts also have the authority and the trust of the patients: what they say, matters. For example, in a study of 483 melanoma patients, it was reported both immediately after the diagnosis and at a 10-year follow-up, that the two most frequently endorsed ways of coping were "trusting my doctors" and "following the medical advice exactly" (Zschocke et al., 1996). Teaching SSE to patients has an impact on their SSE performance (Hay et al., 2006; Lee et al., 2008; Oliveria et al., 2004; Phelan et al., 2003; Robinson et al., 2014; Turrisi, Hultgren, Mallett, Martini, & Robinson, 2015; Weinstock et al., 2007). However, the reality of many healthcare systems around the world is that the physicians have little time to teach prevention skills to every patient (Østbye et al., 2005; Yarnall, Pollak,

Østbye, Krause, & Michener, 2003). Fortunately, doctors do not necessarily need to teach SSE in detail as interventions carried out by nurses or trained ancillary staff are typically very effective (Geller et al., 2004; Hay et al., 2006; Oliveria et al., 1999; Phelan et al., 2003). Moreover, physicians who verbally recommend SSE to patients (even without illustrating how to perform a skin exam) or who simply mention SSE as an option, have the potential to increase the practice of SSE among patients, although to a lesser degree than a full SSE education (Aitken et al., 2004; Manne et al., 2004; Manne & Lessin, 2006; Robinson et al., 1998; Weinstock et al., 1999). Consequently, the role of physicians may be to simply encourage and support self-examination, with nurses or trained ancillary staff providing more detailed instructions.

Given how little is known about physician support of SSE and patient self-efficacy for this potentially life-saving practice, the current project will focus on exploring the link between the two. The first study objective is therefore to prospectively assess self-efficacy for SSE among patients diagnosed with melanoma. The second objective is to compare the trajectory of self-efficacy of patients as a function of perceived physician support of SSE practice. Finally, the third objective is to evaluate whether medical support of SSE, conceptualized as physicians' encouragement of the SSE practice as reported by the patients ("physician support of SSE") and the education provided to the patients by trained ancillary staff, relates to patients' self-efficacy levels over time.

It is hypothesized that:

1) Self-efficacy for SSE will be higher immediately after the SSE-intervention than before the intervention.

2) Self-efficacy for SSE will remain higher at three- and twelve-month post-intervention follow-ups as compared to the pre-education level.

3) The level of perceived physician support of SSE at baseline will be associated with the level of patient self-efficacy for SSE over the following 1.5 years.

Methods

Participants

Individuals diagnosed with melanoma recruited from two major teaching hospitals in Montreal, Canada, participated in the current project after obtaining an approval from the hospitals' research ethics boards. The eligibility criteria included the ability to speak and read English or French, being at least 18 years of age, and having a medically confirmed diagnosis of melanoma.

Procedure

Design. The present study employed a repeated-measures, longitudinal design with four assessment points (baseline, Time 2, 3 and 4) over the span of 18 months. In order to reduce potential socially desirable responding likely to emerge in longitudinal research, the study was designed in such a way that the patients would interact with different research staff throughout the study. They were also repeatedly reassured that their answers will remain confidential. The initial recruitment was conducted by research assistants (RAs), who obtained informed consent and administered baseline questionnaires in person. A different RA, who was not involved in recruitment or data collection delivered the dermatological intervention on how to perform SSE at Time 2. Questionnaires used for Time 3 and Time 4 assessments were sent by mail. All participants received questionnaires to fill out and were offered a participation in an education session on melanoma and SSE as part of the study. The physicians' behaviour was not manipulated in any way.

Recruitment. Patients were notified by the clinic coordinator about the possibility of taking part in this study. Recruitment fliers were posted in the waiting areas of the two melanoma clinics and clinic coordinators advertised the study to all patients. Patients had the possibility of signing up on the premises or they could take home the study materials (consent forms and baseline questionnaires) and later contact the study coordinator via phone to express interest in participating. The research assistants present in the clinic were also able to approach the patients in the waiting room inviting them to participate. Written informed consent to participate was collected from individuals, who expressed interest in participation in the study. The participants received a questionnaire package to be completed after their clinical appointment or to be returned in a pre-addressed pre-stamped envelope.

Assessment time points. Participants were encouraged to schedule their educational intervention three months after study enrolment, but were allowed to schedule the intervention concurrently with their next clinical appointment. They completed the second battery of questionnaires in conjunction with the education session at Time 2 (which included a pre-intervention and post-intervention assessment of self-efficacy). Follow-up assessments took place at 3 months (Time 3) and 12 months (Time 4) post the education session. Participants received $30 as compensation for filling in questionnaires at each time point.

Intervention. In conjunction with Time 2 assessments, participants met with a trained RA who provided a standardized 20-minute individual educational session on the early signs of melanoma and a whole-body skin self-examination derived from empirical evidence and best practice guidelines (Körner et al., 2013). During the session participants received printed visual aids for detecting melanomas, an SSE brochure developed by the Canadian Cancer Foundation, as

well as a body map diary to record their SSE practice at home (Körner, Czajkowska, Moumne, & Wang, 2010; Körner et al., 2013).

Measures

Sociodemographic and illness-related information was collected at baseline using a self-report questionnaire. Medical information including the stage of melanoma and the time since diagnosis were retrieved from patients' medical charts and double checked against the hospitals' tumour registries. Physician Support of SSE (as reported by the patients) was assessed using the 6-item Likert-type *Physician Support of SSE Scale* concerning a physician advice and ecouragement of SSE (Coroiu, Garland, Donovan, Czajkowska, & Körner, 2016). Sample items include "My physician has recommended that I do skin self-exams" and "My physician has asked me if I have questions or concerns about examining my skin." The internal consistency of the scale at baseline was excellent ($\alpha = .94$) and there was no significant difference in mean scores between the English- and French-speaking subsamples ($t(226)=1.42$, $p = .16$). SSE-related self-efficacy was assessed using a 5-item Likert-type *Self-efficacy for Skin Self-Examination Scale* measuring participants' self-confidence in conducting a thorough SSE and recognizing a potentially cancerous lesion (Karapetian, Czajkowska, Coroiu, DiMillo, & Körner, 2016). Sample items are "I am confident that I can do one skin self-exam every month and "I can recognize suspicious changes on my skin." The internal consistency of the scale at Time 1 was acceptable ($\alpha = .74$). There was no significant difference in mean scores between the English- and French-speaking subsamples across all time points.

Results

The sample consisted of 242 patients diagnosed with melanoma. Three hundred and ninety-seven individuals were initially approached by a research assistant or approached the RA

themselves for study participation. Thus, the resulting response rate of 61%. Whereas 116

refused to participate, 24 were not eligible and 15 were unavailable due to other reasons (e.g.,

they went into surgery after speaking to the clinic coordinator but before the research assistant

had a chance to recruit them). The average age was 59.48 years (SD = 13.84) ranging from 26 to

92 years of age. Gender was nearly equally distributed with 50.4 % males, 49.2% females and

one person, who did not disclose their gender. Fifteen percent were diagnosed with melanoma in

situ (stage 0), 48.7% with stage I, 18.7% with stage II, 6.2% with stage III and 3.6% with stage

IV. Eighty-seven percent of participants returned for the intervention within 6 months.

To address the first objective of prospectively assessing self-efficacy for SSE, descriptive

indices such as means, medians, standard deviations as well as minimum and maximum values

were computed for the entire sample (see Table 1). Overall, mean and median self-efficacy

increased significantly after the education for the entire sample. Immediately after the

intervention not a single participant scored 0 on the measure of self-efficacy, which was the only

assessment when this was the case.

To assess the immediate effects of the intervention and test Hypothesis 1, a manipulation

check (a paired-samples t-test) was performed comparing scores on Self-efficacy for Skin Self-

Examination Scale immediately before and after the educational intervention at Time 2. There

was a significant difference in self-efficacy from before ($M = 6.47$, $SD = 2.08$) to after ($M = 9.93$,

$SD = 2.25$) the intervention, ($t(148) = -19.39$, $p < .001$) representing a 23% increase in SSE self-

efficacy. Furthermore, the increase in SSE self-efficacy remained significant at 3 months ($M =$

10.05, $SD = 2.44$; $t(160) = -18.08$, $p < .001$) and at 12 months post-intervention ($M = 9.43$, $SD =$

2.70; $t(140) = -14.49$, $p < .001$) thus supporting Hypothesis 2.

In order to test Hypothesis 3, Time 1 data for the perceived physician support of SSE (M = 9.51, SD = 6.77) were used to form two patient groups, classifying participants in the bottom third of the distribution as "low" (M = 6.62, SD = 2.74) and the top third as "high" in perceived physician support of SSE (M = 9.00, SD = 2.32). The levels of self-efficacy for SSE reported for each group over time are shown in Table 2 and Figure 1. A one-way repeated-measures ANOVA compared the effect of the perceived physician support of SSE on self-efficacy at baseline, immediately before the education as well as three and twelve months after the education. Age, gender, education, cancer stage and time since diagnosis were entered into the model as covariates but none was significant.

Results showed significant between-subjects effects of time and perceived physician support of SSE on self-efficacy ($F(3, 62)$ = 3.06, p =.03, η_p^2 = .13 and $F(3, 62)$ = 4.64, p = .005, η_p^2 = .18 respectively) indicating a significant difference between groups. Mauchly's test of sphericity was not significant, indicating that sphericity could be assumed when interpreting within-subject effects ($\chi^2(5)$ = 2.76, p = .74). Within-subject tests revealed significant main effects of time ($F(3, 192)$ = 3.51, p = .02, η_p^2 = .05) as well as an interaction between time and perceived physician support of SSE ($F(3, 192)$ = 5.16, p = .002, η_p^2 = .08). The within-subject trend analyses showed a significant linear effect of time ($F(1, 64)$ = 8.00, p = .006, η_p^2 = .11) as well as age ($F(1, 64)$ = 6 .65, p = .01, η_p^2 = .09). Similarly, patient-reported physician SSE support showed a significant linear ($F(1, 64)$ = 5.78, p = .02, η_p^2 = .08) as well as quadratic trend ($F(1, 64)$ = 9.47, p = .003, η_p^2 =.13). Post-hoc pairwise comparisons conducted using Bonferroni adjustments showed the perceived low vs. high perceived support of SSE groups to differ significantly in their self-efficacy levels ($M_{LowSupport}$ = 7.79 vs. $M_{HighSupport}$ = 9.71, p= .001) thus supporting Hypothesis 3. Follow-up t-tests showed that the high perceived physician support of

SSE group reported higher self-efficacy for SSE at baseline ($t(157) = -5.92$, $p < .001$),

immediately before the intervention ($t(112.93) = -2.42$, $p < .02$), and 12 months after the

intervention ($t(102) = -2.43$, $p < .02$). The low/high groups did not differ significantly at the

three month follow-up, ($t(114) = -1.86$, $p = .07$; for changes in self-efficacy over time, see Figure

1).

Discussion and Conclusion

Discussion

   The present study represents a prospective examination of self-efficacy specific to SSE

among individuals diagnosed with melanoma. An educational intervention teaching participants

to examine their own skin for cancerous changes was followed by an immediate increase in

patients' self-efficacy for SSE, which was maintained three and twelve months after the education.

The levels of self-efficacy measured after the intervention were significantly higher compared to

levels obtained prior to the intervention, lending support to our second hypothesis. Furthermore,

physician support of SSE, as reported by the patients, was associated with higher self-efficacy after

controlling for age, gender, tumour stage and, time since diagnosis. This association between

perceived physician SSE support at the onset of the study and self-efficacy remained significant

throughout the duration of the follow-up suggesting a durable relationship between the two, thus

confirming our last hypothesis.

   In line with previous research, our results suggest that specialized training on SSE and

early signs of melanoma as well as physician SSE-specific support is associated with patients'

higher self-efficacy for this health behaviour (Auster et al., 2013; Hay et al., 2006; Kasparian et

al., 2010; McLoone et al., 2013; Mujumdar et al., 2009). Participants reporting low as opposed to

high physician support for SSE differed significantly in their level of SSE-specific self-efficacy at

baseline, before the intervention, and at the twelve-month follow-up, but not at the three-month follow-up. These findings suggest that the educational intervention has the potential to boost patients' self-efficacy to a sufficiently high level that no differences between groups remain, however, this boost may be only temporary if not strengthened by physician support. In other words, both education and physician support may contribute to SSE-specific self-efficacy, with education alone not being sufficient to sustain the high level of self-efficacy likely needed for long-term secondary prevention of melanoma through SSE.

Nevertheless, future research on how other forms of social support may moderate the relationship between education and self-efficacy specific to SSE is needed. For instance, in a recent randomized controlled trial of couples learning SSE together, those reporting fewer "activities with a partner" and lower "happiness" within a couple showed greater benefits in terms of self-efficacy level of the patients after participating in an SSE education (Hultgren, Turrisi, Mallett, Ackerman, & Robinson, 2016; Robinson et al., 2014; Turrisi et al., 2015). In our own sample data analyses of participants, who were in a romantic couple during the study (n=137) revealed that a perception of SSE support from the romantic partner and the participants' comfort with being assisted with SSE by their partner independently predicted patients' SSE self-efficacy, underscoring the importance of social support from a romantic partner [58]. Further examination of other types of support in addition to physician and partner support of SSE is needed to better understand the effects of social support on individual's self-efficacy for critical health behaviours, such as SSE.

To our knowledge, this study is the first to report on skin examination self-efficacy over a long duration (up to 18 months, including 4 time points and 5 assessments) and to compare participants based on a level of perceived physician support specific to SSE. The support of skin self-examination was not manualized in the current study, allowing for an examination of the

support the patients usually receive in clinics. It is therefore important to remember when interpreting the results that the physician SSE support measure assesses the participants' *perception* and may not reflect the amount of support the patients are actually offered by their physicians. Although such personal perceptions represent the fundamental blocks of individuals' self-views (e.g., as is the case of self-efficacy) (Swann Jr, Chang-Schneider, & Larsen McClarty, 2007), future research may benefit from contrasting patients' perceptions of physician support of SSE with the physicians' self-reports or third-party observer ratings. Similarly, future research would also benefit from examining the impact of physician support of SSE practice apart from the effects of an educational program. Additionally, it may be of interest to examine whether sociodemographic characteristics of the physicians would influence the patients' perception of their supportiveness. Furthermore, future research may benefit from assuring equal number of participants at each cancer stage in order to analyse the potential relationship between the stage and SSE self-efficacy. Additionally, relating the patients' level of self-efficacy to cancer stage as they progress from less to more advanced may also provide valuable information. For instance, patients with a more advanced disease may be less convinced that SSE has the potential to save their lives and therefore they may not even be interested in learning about this practice, which would likely impact their self-efficacy.

Conclusion

Based on the results presented, it may be concluded that educating patients on early signs of melanoma and instructing them on how to perform a self-exam can increase their self-efficacy for this health behaviour over the course of a year. Additionally, perceived physician support of skin self-examination was found to be associated with patients' level of self-efficacy during melanoma follow-up care, underscoring the importance of physician-patient relationship in

achieving sustained high levels of self-efficacy. Future longitudinal research focusing on objective (as opposed to patient-perceived) levels of SSE support by the physicians would be a commendable next step necessary to conclude that physician support can indeed increase patients' self-efficacy for SSE as well as to optimize the SSE practice.

Practice Implications

Individuals diagnosed with melanoma may experience a long-term boost in self-efficacy for skin self-examination if they are provided with appropriate education and physician support. Although further research is necessary to demonstrate a causal link between the two, the present findings suggest an association between physicians' encouragement, guidance, and support regarding SSE and patients' confidence to conduct effective, regular, whole-body skin self-exams, and in turn effective actual self-examination behaviour (Mujumdar et al., 2009).

Physicians caring for melanoma survivors should be aware of this opportunity to facilitate the secondary prevention of melanoma. Adding training on effective strategies to medical schools' curricula may be one way to improve future physicians' ability to convey the importance of SSE for this population and boost patients' confidence in their ability to detect melanoma. Similarly, educating physicians already in practice may bring more immediate effects in terms of doctors' ability to increase patients' self-efficacy for SSE. Efforts should be made to include education for the physicians, for example through workshops offered at scientific conferences for practitioners or as an adjunct to national educational campaigns, such as Melanoma Monday - an annual event taking place every first Monday of May filled with activities to raise awareness about the seriousness of melanoma, inform the public about the dangers of skin cancer, effective prevention and self-detection (American Academy of Dermatology, 2018a; Canadian Dermatology Association, 2014).

Table 1: Self-efficacy for Skin Self-Examination over time (entire sample)

	Time 1	Time 2	Time 2	Time 3	Time 4
	Baseline	Pre-education	Post-education		
N	232	177	158	169	158
Mean	7.41	6.51	9.92	10.08	9.49
Median	8.00	6.00	10.00	10.00	10.00
SD	2.93	2.02	2.25	2.43	2.70
Minimum	.00	.00	4.00	1.00	.00
Maximum	15.00	12.00	15.00	15.00	15.00

Table 2: Self-efficacy for Skin Self-Examination among the subsamples reporting "low" vs. "high" physician support of Skin Self-Examination at baseline.

	Time 1		Time 2 Pre-education		Time 2 Post-education		Time 3		Time 4	
Support level	Low	High	Low	High	Low	High	Low	High	Low	High
N	79	80	64	54	59	45	61	55	53	51
Mean	6.62	9.00	6.40	7.30	10.02	10.38	9.75	10.62	9.15	10.45
Median	7.00	9.00	6.00	7.00	10.00	10.00	10.00	11.00	9.00	10.00
SD	2.74	2.32	2.33	1.66	2.65	1.87	2.85	2.05	3.39	1.80
Minimum	.00	3.00	1.00	4.00	5.00	6.00	1.00	5.00	.00	7.00
Maximum	14.00	15.00	12.00	12.00	15.00	15.00	15.00	15.00	15.00	15.00

Figure 1: Self-efficacy over time for the groups with "low" vs. "high" physician support of SSE

Note. The self-efficacy scores of groups with low vs. high physician support of SSE differed significantly at a $p = .001$ level.

Linking chapter 3 and chapter 4

Chapter 3 reported on SSE-specific self-efficacy in patients with melanoma who received an educational intervention modeling best-practice care. All participants were educated on the early signs of melanoma and how to detect them through skin self-examination (SSE). The results demonstrated that following the educational session patients' level of self-efficacy for SSE improved by 23% and this increase was retained 3 and 12 months later. Moreover, the patients' perception of physician support of SSE corresponded to the level of self-efficacy, with higher patient-reported physician support being related to higher SSE self-efficacy. The above-mentioned findings underscore the importance of physician support of SSE for patients' self-efficacy.

The next step in understanding the role of the physician and self-efficacy is to take a closer look at a way in which these two variables may work together to predict SSE. Chapter 4 shows that not only perceived physician support of SSE and self-efficacy are associated with SSE behaviour but also reports on a mediation whereby self-efficacy partially explains the relationship between physician support of SSE and actual SSE practice. The cumulative findings of these two chapters may suggest that the role of the physician could be both direct (by encouraging SSE) and indirect (by increasing patients' confidence in their ability to perform SSE).

Chapter 4

Self-efficacy mediates the relationship between physician support and skin self-examination in patients with melanoma.

Zofia Czajkowska, Maida Sewitch, Nathan C. Hall, Annett Körner

Abstract

Background: As melanoma represents the most lethal form of skin cancer and comes with a life-long elevated risk for recurrence and new primary tumours, continued skin self-examination (SSE) is critical to facilitating early detection and treatment. Physician support of patients with melanoma is a scarcely researched topic and yet it may be important for uptake and maintenance of regular SSE. By contrast, self-efficacy specific to SSE is a known predictor of SSE and it may be affected by the physician behaviour. Thus, it is hypothesized that the effects of perceived physician support on this health behaviour should be not only beneficial but also mediated by patients' self-efficacy for skin self-examination.

Methods: Multiple regression models to evaluate potential mediation as per Baron and Kenny (1986) were employed to examine the extent to which the anticipated positive effects of perceived physician support for SSE on SSE behaviour were mediated by patient SSE self-efficacy. Bootstrapping analyses with 5000 iterations were conducted to confirm the significance of the hypothesized indirect effect.

Results: Self-efficacy partially mediated the relationship between perceived physician support of SSE and SSE behaviours (β = .29, $t(145)$ = 3.19, $p < .01$ before adding self-efficacy into the model versus β = .18, $t(144)$ = 2.06, p = .04 after adding the mediator) as supported by a significant Sobel's test of the indirect effect (z = 2.64, $p < .01$, 95% CI = .05 - .20).

Conclusion: As hypothesized, patient self-efficacy was found to partially explain the beneficial link between the perceived physician support of SSE and the practice of skin self-examination among patients diagnosed with melanoma.

Implications for practice: Physicians are encouraged to consider the potential benefits of their support for increasing the frequency of SSE behaviour by way of fostering patient confidence in their own ability to perform skin self-exams.

Keywords: melanoma, self-efficacy, physician support, skin self-examination

Introduction

Cutaneous melanoma is the fastest growing and most lethal cancer of the skin (Trask et al., 2001). It is diagnosed around the world and its incidence has been increasing for decades (Ferlay et al., 2013; Geller, 2009). In North America, the incidence of melanoma continues to rise annually by 2-3% (American Cancer Society, 2018a; Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017; Siegel et al., 2016). The current lifetime risk of developing a melanoma is 1 in 42 female and 1 in 27 male fair-skinned Americans whereas in the 1930s it was about 1 in 1 500 fair-skinned Americans (American Cancer Society, 2018a; Rigel, 2010). Although the overall five-year survival rate exceeds 90%, the death toll of melanoma remains significant (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017; Howlader et al., 2013; Siegel et al., 2016). Melanoma accounts for 75-90% of all deaths attributed to skin cancer in the United States (American Academy of Dermatology, 2018d; Garbe et al., 2010; Trask et al., 2001). Survival rates depend largely on the tumour stage at diagnosis. More specifically, whereas diagnosis at Stage I is associated with 86 to 95% five-year observed survival rate, at stage II it is 40 to 67%, at stage III it is 24 to 68% and at stage IV it is only 15 to 20% decreasing further to 10-15% for the 10-year observed survival rate (Balch, Gershenwald, Soong, Thompson, Atkins, Byrd, Buzaid, Cochran, Coit, Ding, et al., 2009). As such, tumour detection and treatment at earlier stages represent a critical focus in melanoma research due to clear implications for survival.

Once diagnosed, patients remain at increased risk for subsequent tumours for the rest of their lives (Ferrone, Ben Porat, Panageas, Berwick, Halpern, Patel, & Coit, 2005; Manganoni et al., 2007; Uliasz & Lebwohl, 2007) with up to 13% of patients diagnosed with melanoma experiencing recurrence or developing a second primary tumour (Doubrovsky & Menzies, 2003; Robinson et al., 2016; Uliasz & Lebwohl, 2007). Furthermore, for patients with two primary

melanomas, the 10-year risk of developing a third lesion is estimated at nearly 28% (Doubrovsky & Menzies, 2003). Given this high risk, secondary prevention is of utmost importance for melanoma patients so as to increase awareness of early signs of the disease and promoting behavioural practices favouring early detection such as clinical skin exams by medical professionals or skin self-examination (Markovic et al., 2007).

Whereas clinician-led exams may result in detection of thinner, less advanced tumours, that are more amenable to treatment (Brady et al., 2000; Carli et al., 2003; Epstein et al., 1999; Schwartz et al., 2002), they are unlikely to include an examination of the patient's entire body and can miss 1 in 3 melanomas (Aldridge et al., 2013). Moreover, research has shown that most melanomas are first detected by patients themselves or those in close contact with them in everyday life (Brady et al., 2000; Carli et al., 2003; Dalal et al., 2008; Epstein et al., 1999). Skin self-examination has been linked to an increased likelihood of finding a less advanced tumour and consulting a physician sooner (Carli et al., 2003; Pollitt et al., 2009; Titus, 2013). Given that self-detection better predicts survival than physician-detection (Dalal et al., 2008), the practice of skin self-examination (SSE) represents an important step toward early diagnosis and treatment, as well as increased survival chances for patients with melanoma (Berwick et al., 1996; Berwick et al., 2016; Dalal et al., 2008; Geller et al., 2006; Titus, 2013).

Conducting a skin self-exam involves checking the skin of one's entire body including places that are difficult to see (e.g., upper back, neck, top of head, foot soles); thus requiring some physical agility and the assistance of a mirror or a partner (American Academy of Dermatology, 2018b). In addition to knowing what to do, the individual must know how to recognize melanoma and differentiate it from regular moles based on the (a)symmetry, border,

colour, diameter, and evolution of the nevus over time (American Academy of Dermatology, 2018e). Despite the necessity of continuous skin self-examination for secondary prevention of melanoma, SSE is not easily accomplished and sustained adherence can be a challenge (Bichakjian et al., 2011; Coit et al., 2009) as indicated by statistics showing self-examination to be regularly conducted by only 10-20% of melanoma survivors (Berwick et al., 1996; Coups et al., 2016; Manne & Lessin, 2006; Mujumdar et al., 2009).

Among sociodemographic factors associated with more SSE are younger age, being female, greater income, and a higher level of education (Carli et al., 2003; Coups et al., 2016; Manne & Lessin, 2006; K. A. Miller et al., 2015; Robinson et al., 2002; Robinson et al., 1998). One of the most robust predictors of SSE reported in published research to date is self-efficacy, a concept reflecting one's confidence in the ability to perform SSE correctly (Coups et al., 2016; Hay et al., 2006; Kasparian et al., 2012; Kasparian et al., 2010). Findings further show SSE self-efficacy to mediate the relationship between education (about melanoma and SSE skill acquisition) and SSE practice. For instance, recent research shows higher self-efficacy for recognizing an abnormal skin nevus to mediate the relationship between training to recognize suspicious-looking nevi and the correct identification of a common vs. atypical mole (John, Jensen, King, Ratcliff, & Grossman, 2017). Similarly, Hay and colleagues found self-efficacy to mediate the relationship between an intervention that consisted of providing a photobook with each participant's pictures of their whole body and their subsequent SSE practice at the 4-month follow-up (Hay et al., 2006).

In addition to existing research on the positive effects of melanoma patient education programs on SSE practice (Henrikson et al., 2018; Wu et al., 2016), limited research has further explored the role of a patient's physician in promoting acquisition and maintenance of SSE

practice among individuals diagnosed with melanoma. For instance, physician recommendation of SSE has been associated with the practice of self-exams (Manne & Lessin, 2006), e.g., even only briefly mentioning self-examination to their patients corresponded to more SSE practice (Aitken et al., 2004). With respect to potential explanations for why these physician behaviours affect patient SSE, possible suggested mediators include perceived trust, in their doctors and intentions to adhere to physician instructions (Zschocke et al., 1996). However, given demonstrated empirical links between patient self-efficacy and SEE behaviors (Czajkowska, Hall, Sewitch, Wang, & Körner, 2017) it is also possible that such physician support promotes this health behaviour by empowering patients with information and either explicitly or implicitly encouraging them to feel more confident and to assume greater responsibility for their health (Arora, Weaver, Clayman, Oakley-Girvan, & Potosky, 2009). To examine this hypothesized mediational process, the present study examined the extent to which the proposed beneficial effects of physician support on SSE practice in a hospital-based sample of patients with melanoma were mediated by their SSE self-efficacy.

Methods

Participants

Three hundred and ninety-seven individuals were approached by research assistants for study participation in two major teaching hospitals in Montreal, Canada. Due to 116 refusals, 24 not being eligible, and 15 being unavailable for other reasons (e.g., going into surgery before the research assistant had a chance to fully explain the study), the final study sample consisted of 242 individuals. The eligibility criteria included the ability to speak and read English or French, being at least 18 years of age, and having a medically confirmed diagnosis of melanoma.

Procedure

    Design. A repeated-measures, longitudinal design with 4 time points over the span of 18 months (Time 1- baseline, Time 2, 3, and 4) has been used. Time 2 took place 3-6 months after the initial baseline assessment as it was linked to participants' clinical follow-up appointments. While a third of the participants completed Time 2 assessment within three months, 87% completed it within six months after enrollment in the study. In addition to the assessment at Time 2, an educational intervention on the signs of melanoma and how to perform SSE was also administered at Time 2 by a dermatology-trained research assistant. The Time 3 assessment was conducted three months after the Time 2 intervention and Time 4 took place 12 months after the intervention. The current research reports on analyses using the data gathered at Time 4 (15-18 months after baseline).

    Recruitment. Prior to the commencement of the study, approval from the hospitals' research ethics boards was obtained. Patients were notified by the clinic coordinator about the opportunity to participate in this study with study materials, including posters and bookmarks, made available in clinic waiting rooms. Sign-up sheets were available from the clinic staff upon request with detailed information concerning study protocols provided to interested patients by a research assistant who was available in person or by phone. Once the patient agreed to participate, written informed consent forms were completed with participants being provided a questionnaire package to be completed after their physician visit or returned by mail in a pre-addressed pre-stamped envelope. Follow-up questionnaires were submitted by patients via mail with participants being compensated after each time point by a $30 payment to cover the cost of travel and parking.

Measures

Sociodemographic information (age, gender, years of education, income) were collected at baseline using a self-report questionnaire. Cancer stage was retrieved from patients' medical charts and confirmed in the hospitals' tumour registries. Perceived physician Support of SSE (as reported by the patients) was assessed using the six-item Likert-type *Physician Support of SSE Scale* that concerned physician advice and ecouragement of SSE (Coroiu et al., 2017) and included items such as "My physician has recommended that I do skin self-exams" and "My physician has asked me if I have questions or concerns about examining my skin" ($\alpha = .94$). The patient's report of the last visit with their physician was used in this study. SSE-related self-efficacy was assessed using a five-item Likert-type *Self-efficacy for Skin Self-Examination Scale* measuring participants' self-confidence in conducting a thorough SSE and recognizing a potentially cancerous lesion (Karapetian et al., 2016) that included items such as "I am confident that I can do one skin self-exam every month" and "I can recognize suspicious changes on my skin" ($\alpha = .74$). Whole Body SSE practice was also assesed with a questionnaire asking participants to report how often they examined their head as well as the front and back of their lower and upper body parts (e.g., front of the legs, upper back, top of the scalp, etc.).

Data analysis

Multiple regression analyses were employed to test whether self-efficacy mediated the relationship between perceived physician support of SSE and SSE behaviour (at Time 4) using Baron and Kenny's four-step method (Baron & Kenny, 1986) with bootstrapping additionally conducted to determine the strength of the indirect effect (Hayes, 2009; Preacher & Hayes, 2008). The four criteria for establishing mediation in this study were as follows: (1) physician support of SSE is a significant predictor of self-efficacy (the mediator), (2) physician support of SSE is a

significant predictor of the whole-body SSE (dependent variable), (3) self-efficacy is a significant predictor of SSE, and (4) when both the mediator and the predictor are included in the same regression as predictors, the effect of the predictor is no longer significant or significantly diminished. Multiple regression standardized beta weights were used to evaluate the hypothesized direct and indirect effects (via self-efficacy) of perceived physician support of SSE on SSE practice. Subsequently, a Sobel test (1982) was performed to assess the statistical significance of this hypothesized indirect effect, with the bootstrapping algorithm for the estimation of the *p*-value for the Sobel test conducted with 5000 iterations, 95% confidence intervals (Preacher & Hayes, 2008). Age, gender, education and income were chosen as covariates based on previous research showing these background variables to be potentially related to SSE practice (Carli et al., 2003; Coups et al., 2016; Manne & Lessin, 2006; K. A. Miller et al., 2015; Robinson et al., 2002; Robinson et al., 1998). Data analyses were conducted using SPSS Statistics (version 20) with a Process Procedure for SPSS (release 2.16.1).

Results

The sample consisted of 242 patients diagnosed with melanoma. The average age of the study sample was 59.48 years (*SD* = 13.84) ranging from 26 to 92 years of age. Gender was equally distributed with 50.4 % males, 49.2% females, and one participant, who did not disclose their gender. Participant diagnoses consisted of 15% melanomas in situ (stage 0), 48.7% stage I, 18.7% stage II, 6.2% stage III and 3.6% stage IV melanomas. The mean number of years of completed education was 14.78 (*SD* = 3.50), ranging from 5 to 26 years, which is representative of Montreal, where a majority of individuals over 25 years of age hold a post-secondary degree or certificate (Crespo, 2017). The most commonly reported household annual income reported by over a third of participants was "$80 000 or more" with an overall income range of "$10 000", to "$80 000 or

more". Bivariate correlations with known sociodemographic predictors of SSE (age, gender, education, income) showed that SSE was significantly correlated only with education ($r = -.18$, $p < .05$) therefore it was retained in the subsequent analyses as a covariate. The correlations and beta weights for the key study variables are shown in Figure 1.

The first of the multiple regression analyses showed that the perceived physician support of SSE as reported after the most current clinical appointment was positively associated with whole-body SSE practice at 12 months post patient education about SSE and early signs of melanoma, i.e. at Time 4 ($\beta = .29$, $t(145) = 3.19$, $p < .01$). In the second regression, the physician support of SSE was also found to positively predict patient self-efficacy for SSE at Time 4 ($\beta = .15$, $t(145) = 3.57$, $p < .001$). In the first step of the third regression analysis, SSE self-efficacy positively predicted SSE practice ($\beta = .71$, $t(144) = 4.10$, $p < .001$) and, in the second step, the association between physician support of SSE and SSE practice was significantly weaker ($\beta = .18$, $t(144) = 2.06$, $p = .04$). Bootstrapping analyses showed this indirect effect to be significantly different from zero ($z = 2.64$, $p < .01$, 95% CI = .05 - .20), which further supports the finding that SSE self-efficacy partially mediated the relationship between physician support of SSE and SSE behavioural practice.

Discussion

The aim of the current study was to explore the role of SSE-specific physician support and SSE self-efficacy for participants' SSE practice in a sample of patients receiving melanoma follow-up care. As hypothesized, both perceived physician support of SSE and patient self-efficacy for the practice of SSE predicted skin self-examination behaviors after accounting for significant covariates (i.e., education level). These findings thus support previous research demonstrating a link between patient self-efficacy and SSE practice and also contribute to the existing literature showing a strong relationship between physician support of SSE and actual practice of skin self-exams (Coups et al., 2016; Hay et al., 2006; Kasparian et al., 2012; Kasparian et al., 2010). Further, our mediational findings showing self-efficacy to partially mediate the beneficial effects of perceived physician support of SSE on patients' SSE practice also supported our study hypothesis in suggesting that patient confidence in their SSE abilities is important for their adherence to recommendations regarding continued skin self-exam practice during melanoma follow-up care.

An important distinction should be made between physician support of SSE and educational interventions for patients about SSE and the early signs of melanoma - delivered by others than the treating physician. Past research, has shown that patient self-efficacy for SSE increases immediately after receiving instructions on how to recognize early signs of skin tumours and that such instructions have a relatively long-term effect (Czajkowska, Hall, et al., 2017; Robinson et al., 2017). Moreover, it has been shown that self-efficacy mediates the effects of patient education programs and SSE behaviors (Hay et al., 2006; John et al., 2017). In the present study, despite all participants having received the same educational materials and SSE instructions from a research assistant (trained by a dermatologist) at Time 2, the level of SSE

behaviors reported was still found to vary as a function of the perceived physician support of

SSE and, in turn, by patient SSE self-efficacy. Thus, to our knowledge, this paper is the first to

show that the patients' perceptions of SSE support from their physician, above and beyond of

SSE instructions received, can have a significant impact on their SSE self-efficacy and SSE

practice. This underscores the important role of the dermatologists and general practitioners who

are attending to individuals diagnosed with melanoma.

It is important to note that the support of the physician was not manualized in the present

study in that the physicians did not receive any instructions from the research team on how or

whether to recommend SSE to their patients. Clinical care guidelines recommend that patients in

melanoma follow-up care should be advised to perform regular whole-body skin exams (Coit et

al., 2009; National Comprehensive Cancer Network, 2018). However, the current study did not

ask the treating physicians if and how they addressed the need for continuous SSE with their

patients. Consequently, the reports of physician support should be understood as representing the

patients' perceptions of their physician's support of skin self-exams during melanoma follow-up

care. Nevertheless, these findings serve to highlight the predictive utility of patients' self-reports

(Swann Jr et al., 2007). It remains to be empirically tested whether more objective third-party

observer ratings of physician support of SSE have greater or poorer predictive power when it

comes to patients' adherence to this health behaviour. Future research may also focus on

subjective reports of the physicians to compare and contrast it with patients' reports and

objective ratings so as to evaluate the implications of congruent or mismatched SSE support

perceptions on patient outcomes.

Another caveat deserving of mention is the cancer stage of the patients. In the current

project, almost half of the participants were diagnosed with a Stage I tumour with an additional

15% being diagnosed as in situ (stage "zero") at the start of the study. Accordingly, it is possible that both physicians' and patients' beliefs about the utility of conducing SSE at these early cancer stages may have influenced their likelihood of recommending SSE/ following recommendations regarding SSE. For instance, physicians may make efforts to minimize their patients' anxiety by reassuring the patients that they had undergone a successful treatment and "there is nothing to worry about". By providing such reassurance they may inadvertently minimize the importance of ongoing vigilance and regular long-term SSE practice. The way doctors communicate with their patients matters (Arora et al., 2009; Robinson, Mallett, Turrisi, & Stapleton, 2009). Additionally, future research may greatly benefit from longitudinal controlled projects focusing on both education and physician support of SSE to elucidate their independent contributions to the SSE practice among patients with melanoma.

Finally, the present findings demonstrate the importance of informing physicians that their support of SSE in melanoma patients has clear implications for their patients' self-confidence in their ability to perform critical skin self-examination as well as for the frequency of SSE behaviours. As such, efforts to educate physicians as to the impact of their SSE support is critical given that patients' perceptions of their physicians' support can have a significant impact on skin self-exams and thus on potentially earlier tumour detection and treatment, which is related to long-term survival in this high-risk population (Berwick et al., 1996; Berwick et al., 2016; Brunssen et al., 2017).

Figure 1. Direct and indirect effect of Physician Support of SSE on Whole Body SSE practice
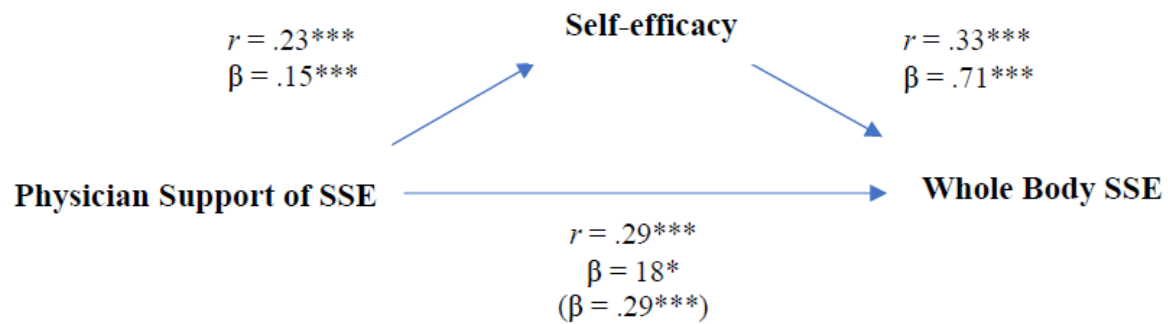
Note: Self-efficacy partially mediated the association between Physician Support of SSE and Whole Body SSE. β in brackets signifies the β before the addition of the mediator.

***$p < .001$

Chapter 5

Summary, Discussion, and Conclusions

Summary of relevant findings

This dissertation provided a thorough review of the literature on melanoma and its prevention with an emphasis on the role of the physician in promoting secondary prevention through skin self-examination (SSE). The three manuscripts that followed contributed to our understanding of the importance of patient education, self-efficacy specific to SSE as well as the potential role of the physician in promoting optimal self-screening for early signs of melanoma among its survivors.

Manuscript one (chapter 2) made a contribution to the field of health care research by validating a brief version of a widely used measure of perceived autonomy support, namely the Health Care Climate Questionnaire - HCCQ (Williams, Freedman, et al., 1998; Williams et al., 1996) in a Canadian sample of individuals diagnosed with melanoma. More specifically, the HCCQ assesses patients' perceptions of the support by the physician (i.e., feeling understood, accepted, being encouraged to take an active role in managing one's health, trusting the doctor, etc.). A brief, 6-item version of this measure has been suggested for use by the authors of the original questionnaire. However, it had not been validated prior to the here reported analyses. In addition to demonstrating the scale's internal consistency, structural and construct validity as well as reliability it has been translated into French (the full scale of 15 items) in order to facilitate research in francophone and bilingual (English-French) environments. The English and French versions of HCCQ appear to be equivalent and as such may be considered valid for use in both languages with melanoma patients and other populations with similar characteristics.

Manuscript two (chapter 3) focused on patient education and self-efficacy. More specifically, the findings suggest that a brief educational session about the detection of early signs of melanoma via regular whole-body self-exams contributed to an increase in patients' self-efficacy for SSE. Further, physician support specific to SSE practice was also associated with the patients' self-efficacy. Consequently, the third manuscript (chapter 4) focused on testing a model in which both physician support and self-efficacy predicted skin self-examination behaviours among patients with melanoma. More specifically, a mediational pathway whereby the level of self-efficacy explains the relationship between physician support of SSE and SSE behavioural practice has been tested. The results supported a partial mediation. These findings suggest that the role of the physician in promoting secondary prevention of melanoma via skin self-exams may be both direct (by recommending and encouraging SSE) and indirect (by increasing patients' confidence in their ability to perform SSE).

Contributions to the field of research

The findings reported in all three manuscripts have made original contributions to the existing literature. The first manuscript provided the results of a validation of a scale that has been in use for over 20 years. The review of the literature on Health Care Climate Questionnaire revealed multiple versions of the scale with different numbers of items and different response options but only very scarce validation data (Kasser & Ryan, 1999; Williams et al., 1999; Williams, Freedman, et al., 1998; Williams et al., 2002; Williams et al., 1996; Williams, Rodin, et al., 1998). The validation of the 6-item HCCQ, a brief version recommended by the original authors, will allow the psychometrically sound assessment of this construct and, has the potential to facilitate the comparability of findings between future studies. Moreover, this doctoral project has provided the research and the clinical communities with a validated French version of the 6-

item HCCQ as well as with a French translation of the full 15-item scale following a back-and-forth translation protocol for health-related scale (Acquadro, Conway, Hareendran, & Aaronson, 2008; Cha, Kim, & Erlen, 2007), which allows to use and further validate these measures in French and bilingual settings.

The second manuscript was not the first to show that an educational intervention may increase self-efficacy. For instance, Hay and colleagues demonstrated an increase in self-efficacy following a nurse-led education session about SSE four months later (Hay et al., 2006). Similarly, an increase in self-efficacy following an educational intervention at a four-month follow-up was reported by the Robinson group (Robinson et al., 2007a, 2007b). At the time the current project was designed, there was no published research reporting longer-term follow-up results. Thus, the goal of my dissertation research was to provide an account for SSE-specific self-efficacy beyond the previously studied short periods. As such, the level of self-efficacy was examined before, immediately after, at 3 months and 12 months following an educational intervention designed to model best-practice melanoma follow-up care. Since then, Robinson and colleagues have published results from the largest RCT to date following 494 participants for 24 months (Robinson et al., 2014; Robinson et al., 2016). This study had three arms providing educational interventions: a) a face-to-face meeting with an educator, b) reviewing an educational workbook and c) learning via an electronic interactive education delivered on a tablet computer. Over the next 24 months the assessments of self-efficacy every 4 months showed a significant increase in patients' confidence in performing effective SSE (Robinson et al., 2017). The findings of this sole study with a long-term follow-up are corroborated by the here-presented dissertation research showing a sustained increase of SSE-specific self-efficacy over the 12 months after being educated on the detection of

early signs of melanoma through skin self-examination (Czajkowska, Wang, Hall, Sewitch, & Körner, 2017).

Most importantly, the current project provides a unique contribution by demonstrating that the physician support of SSE during melanoma follow-up care was related to even higher levels of SSE self-efficacy in patients, who all received the same education delivered by a dermatology-trained research assistant. While perceiving one's treating physician as generally supportive was not related to SSE behavioural practice, experiencing the physician as being interested in, encouraging, and advising on skin self-exams was associated with more frequent patient self-exams covering more parts of their body – a health behaviour that has been linked to thinner melanomas at diagnosis, getting treatment sooner, and lower risk of melanoma-related mortality (Berwick et al., 1996; Berwick et al., 2016; Carli et al., 2003; Garbe et al., 2007; Paddock et al., 2016; Titus, 2013). Further, this dissertation is offering insight into a possible pathway of this effect: the results suggest that physician support of SSE may be positively related to SSE behaviour because this support improves the patients' SSE-specific self-efficacy, a known predictor of skin self-exams (Coups et al., 2016; Hay et al., 2006; Kasparian et al., 2012; Kasparian et al., 2010).

Implications for clinical practice – the role of the physician

Physicians are able to detect thinner melanomas and consequently facilitate earlier treatment (Carli et al., 2003; Titus, 2013). However, their role in secondary prevention of melanoma is not limited to clinical skin exams. They may improve patient outcomes both through direct detection efforts (i.e., clinical exams) and through encouragement of SSE in order to increase the odds of patient self-detection of tumours in between follow-up appointments. Patients previously diagnosed with melanoma tend to rely on their doctors' advice when it comes to secondary prevention (Zschocke et al., 1996). Physician recommendation of SSE has been

associated with the practice of self-exams (Manne & Lessin, 2006; Rat et al., 2014), e.g., even only briefly mentioning self-examination to the patients corresponds to more SSE practice (Aitken et al., 2004). It is possible that physician support specific to SSE promotes this health behaviour by empowering patients with information and either explicitly or implicitly encouraging them to feel more confident and to assume greater responsibility for their health (Arora et al., 2009). Indeed, this dissertation research showed that SSE self-efficacy partially explains why physician support may predict SSE practice (see Chapter 3). Further, patients' confidence in their ability to perform effective SSE is a strong predictor of SSE practice (Hay et al., 2006; Robinson et al., 2007b), also demonstrated in our study (see Chapter 4). Consequently, given that both patients' self-confidence in performing effective SSE and SSE behaviour itself are associated with physician's encouragement of this practice (Aitken et al., 2004; Manne et al., 2004; Manne & Lessin, 2006; Rat et al., 2014), it is important for physicians to be aware of their power to elicit positive change in their patients at risk for melanoma.

Physicians might benefit from additional training on how to best convey to patients the message that they can examine their own skin effectively and boost patients' confidence in their SSE skills thereby promoting the practice of self-exams among melanoma survivors. This could be achieved by adding training to medical schools' curricula on how to teach about SSE but also how to speak to patients in a way they would feel supported, encouraged and motivated to follow the physicians' advice. Similarly, current practitioners would likely benefit from such training in their professional development efforts, e.g., through workshops offered as a part of ongoing education at conferences as well as the workplace. Additionally, outreach efforts could be made as a part of national educational campaigns for the public, such as Melanoma Monday (American Academy of Dermatology, 2018a; Canadian Dermatology Association, 2014). Regardless of the

circumstance of the training it is important that such trainings be made interactive to allow for practicing of the newly acquired skills, as research suggests that only hands-on interventions have an impact on physicians' medical practice (Davis et al., 1999).

Limitations

Several limitations warrant attention. First, the data in the present analyses are based on a sample of modest size ($N = 242$), which limited the analyses that could be conducted within this doctoral research project. For instance, when performing the confirmatory factor analysis in the validation study there was an acceptable number of data (i.e., a minimum of 10 participants per item and a minimum of 100 data points over all for the CFAs). However, the sample size did not significantly exceed the standard benchmarks (115 in the French subsample, 119 in the English subsample) (Terwee et al., 2007). Second, the examination of construct validity did not include a comparison of the HCCQ to another gold standard measure of "health care climate" or "health care provider support of patient autonomy" as no such measure exists. Thus, construct validity was assessed via correlations of the HCCQ with measures of proximate as well as more distal constructs.

Additionally, it should be noted that the items of the HCCQ seem to be more representative of the quality of the relationship between the physician and a patient rather than the autonomy support. Nevertheless, we retained the phraseology of the original authors referring to "autonomy support" and "health care climate" for the sake of consistency with previous research.

Further, the support of the physician was not manualized in the present study in that the physicians did not receive any instructions from the research team on how or whether to discuss SSE with their patients. Clinical care guidelines recommend that patients in melanoma follow-up care should be advised to perform regular whole-body skin exams (Coit et al., 2009; National

Comprehensive Cancer Network, 2018). However, in the current study the treating physicians were not asked if and how they addressed the need for continuous SSE with their patients. Consequently, the reports of physician support represent the patients' perceptions of their physician's support of skin self-exams during melanoma follow-up care. Patients' reports are important and have a high predictive utility in research (Swann Jr et al., 2007). Still, it remains to be empirically tested whether more objective third-party observer ratings of physician support of SSE have greater or poorer predictive power when trying to understand the role of physician support for patients' adherence to this health behaviour.

Directions for future research

The here-presented findings offer multiple avenues for future research. For instance, a focus on subjective reports of the physicians concerning their general as well as SSE-specific support of the patients could further enlighten our understanding of this factor for secondary prevention of melanoma – especially when compared and contrasted with the patients' reports. Indeed, the existing research suggests that physicians and patients do not perceive patients' reality the same way (S. B. Cohen, Strand, Aguilar, & Ofman, 2004; Efficace et al., 2014). In addition to physician-reports, more objective, third-party ratings may further our understanding of the quality of physician support allowing to evaluate the implications of congruent or mismatched support perceptions on patient outcomes. Further, future research may greatly benefit from longitudinal controlled projects focusing on both education by other health care professionals such as nurses and physician support of SSE to elucidate their independent contributions to the uptake and continued practice of skin self-exams among patients at risk for melanoma. This may also allow to identify specific teachable moments in the illness trajectory as well as to determine if there is

an added benefit of a physician's continued support of SSE behavioural practice as opposed to a one-time advice.

A separate area of research worthy of pursuing may be on physicians' ability and self-efficacy for teaching melanoma survivors about skin self-examination and its importance. Additionally, training physicians to be more empathic and encouraging can have a real impact on patient perceptions of received support, and potentially their motivation to adhere to medical advice (Pollak et al., 2011). More research is needed to examine whether hands-on training of physicians on increasing patients' knowledge and motivation to conduct regular, whole-body SSE would be effective.

Conclusion

Physicians may have the power to impact patients' confidence, motivation and health behaviours, which are likely to result in better patient outcomes. Survivors of melanoma are likely to benefit from additional targeted support, focusing primarily on teaching skills and boosting self-efficacy related to skin self-exams. As such, research is needed to develop effective methods of training physicians so that they too can be empowered with knowledge, skills and confidence in their abilities to support their patients.

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