

The concept Locus of Control (LOC) appeared first in Rotter's (1966) social learning theory and later became a central concept in the field of personality psychology (Goldzweig et al, 2016). The definition of Health Locus of Control (HLC) refers to personal health and health behaviour (Wallston, 2005), a widely accepted concept in studies of individuals' beliefs based on past experiences in controlling health issues (Kulpa et al, 2016). According to Rotter's theory, the patients' tendency to regard health related events is characterized and controllable by two different forces: internal locus of control (ILC) and external locus of control (ELC). Internal reinforcement occurs when one believes that one's behaviour is in one's own control and that he or she is in control of his or her health, while external reinforcement is present when a person believes that his or her health status is influenced by the actions of other people (Wallston et al, 1994). The Multidimensional Health Locus of Control form C (MHLC-C), developed by Wallston and colleagues in 1994, is a condition-specific LOC scale measuring LOC for people with any medical or health related condition. It measures ILC and ELC, the latter including three subgroups (having faith in doctors, having faith in other people, and believing in chance and fate).

Studies have revealed that cancer patients with a higher ELC are significantly more often using sources of information as well as being significantly more in need for additional information than those with ILC (Keinki et al, 2016). Another study (Goldzweig et al, 2016) found a significant relationship between perceived threat of illness and depression among cancer patients reporting low levels of ILC. Findings in this study also distinguish between ILC and ELC, and the authors suggest that ILC may be more appropriate and helpful to master the cognitive perception of the threat of illness than ELC. Additionally, Marton et al (2021) found that people with a lower score in ELC (having faith in other people) were more likely to prefer an active role or collaborative role in medical decision-making. The authors suggested that it may be so that people do not fully grasp the impact that other people and doctors could have on their health.

Studies on psychological distress and somatic symptoms among patients with cancer show high levels of distress with emotional and physical problems being the main problems (Chi and Demiris, 2016; Hjörleifsdóttir et al, 2019; Peters et al, 2020). Findings in previous studies suggest that there is a need for an early identification of patients with high risk for psychological distress, and factors which may contribute to the development of depression and anxiety should be considered. These may be physical and social factors, symptoms

related to cancer and its treatment, treatment setting, and type of cancer and time since diagnosis (Zhang et al, 2015). Kulpa et al (2014) support the above-mentioned results from previous studies by showing in their study on patients with cancer that confirming that the lower is the severity of anxiety and depression, the higher is the degree of ILC.

To our best knowledge, only a few studies have considered a correlation between HLC and somatic symptoms (Basinska and Andruszkiewicz, 2012). In Zhang et al's (2015) study on patients with cancer who were receiving chemotherapy treatment it was found that more self-efficacy meant less symptoms and less interference with daily life, but anxiety and depression were positively associated with symptom distress. However, more severe symptoms were shown to be associated with age, gender, and the stage of the disease. Gogou et al (2015) found, in a study of patients who were receiving radiotherapy treatment for their cancer, that symptom complications such as fatigue, sleeplessness and pain were significantly associated with a poor quality of life (QoL) and high levels of anxiety. Furthermore, Marijanović et al (2017) compared HLC between patients with early stage, and later stage cancer and its correlation to early attendance to hospital. Their conclusion was that HLC was not a statistically significant predictor of early admittance, neither was there an indication of a relationship between depression and time of arrival to hospital. The authors emphasise that more research is needed to make any suggestions on this construct.

From a global perspective, the incidence of cancer will continue to rise, in the year 2008 an estimated 12.7 million individuals were diagnosed with cancer and this number is bound to rise substantially by 2030 (Coleman, 2013). The incidence rate of cancer among the Icelandic population has quadrupled since registration on cancer diagnosis began in 1954, with around 1,500 individuals diagnosed on a yearly basis (Jónasson and Tryggvadóttir, 2012). Overall, the studies presented above indicate that ILC can be interpreted as having a sense of mastery and control when managing one's own health during the disease and treatment process. In contrast, ELC can be understood as being more likely to rely on others to manage one's own health. HLC is one of the factors that can affect people's ability to cope with cancer and its treatment. More studies are needed on the correlation of anxiety and depression with HLC so that the severity of anxiety-depressive disorders can be reduced (Kulpa et al, 2014). Lack of research, in Iceland and globally, on HLC and how it may have an impact on how patients with cancer cope with their often-severe symptoms and its consequences, prompted this study.

Methodology

Aim

The aim of this study was to investigate differences in psychological distress and HLC between cancer outpatients receiving treatment for cancer. A further aim was to describe and investigate correlation between psychological distress and HLC, severity of symptoms, and its interference with daily life. Finally, we explored factors which might contribute to psychological distress.

Study design and setting

This descriptive cross-sectional study was conducted in three oncology outpatient clinics, two in the capital Reykjavík and surrounding communities (situated in the south of the country with 236,518 inhabitants), and one in Akureyri, which is a town serving the north and surrounding communities with 19,573 inhabitants (Statistics Iceland. Inhabitant's overview, 2017).

Participants

Questionnaires were distributed to 300 individuals who were receiving radiotherapy or chemotherapy treatment for cancer. The sample consisted of patients (N=247) with cancer. The participants were eligible for the study if they understood and could speak Icelandic, were 18 years of age or older, and were currently receiving radiotherapy, chemotherapy or palliative therapy as a treatment for cancer.

Study procedures

Nurses at the outpatient clinics approached potential participants for recruitment and informed them of the study. Those patients who were interested were given more detailed information including a specific information letter explaining the purpose of the study, how it would be implemented, how full confidentiality would be secured, and participants'

consent consisted in answering the questionnaire. Completed questionnaires were returned anonymously to the first researcher in a prepaid envelope. Data was gathered over a one-year period during 2016- 2017.

Ethical issues

Ethics approval was obtained from the Icelandic Bioethics Committee according to Icelandic regulations on the scientific study of patients and in accordance with the Declaration of Helsinki.

Instruments

A self-administered questionnaire consisting of four parts was used for the study: The first part included socio-demographic and disease-related information (gender, age, marital status, education, frequency of diagnosis, reason for treatment, type of treatment, and stage of disease).

MHLC-C

The second part assessed participants' belief in control of their own health using the MHLC-C, which was adapted for patients with existing medical conditions. This form consists of 18 items divided into four LC subscales: perception of ILC (6 items); chance (6 items); other powerful, i.e., doctors and health care professionals (3 items); and other people (3 items). The instrument measures four dimensions of MHLC, ILC, ELC (believing in chances, believing in physicians, and believing in others), rated on a six-point Likert scale (strongly disagree to strongly agree). This tool has no cut-off point, and the mean or median score is used for final evaluation (Wallston, 2005).

As stated, the notion of HLC derives from social learning theory and refers to the degree of control that people believe they possess over their personal health (Rotter, 1966; Wallston, 2005). People with high ILC are likely to believe that their personal health related outcomes are mostly determined by their own choices and actions, while those who have high ELC

believe that other powerful people, such as physicians, will determine their health outcome, i.e., what happens to them depends on others' behaviour, coincidences, fate, or luck (Rotter, 1966; Wallston, 2005). The questionnaire was translated in a forward-backward procedure according to guidelines established by the European Organisation for Research and Treatment of Cancer (EORTC) quality of life group (Kuliś et al, 2017). MHLC-C has been found to be a reliable instrument in studies in different countries on people with chronic diseases and cancer showing Cronbach alpha range from 0.79 (Thege et al, 2014), 0.74 (Ubbiali et al, 2008), and 0.90 (Mirzania et al, 2019). A permission for translating and utilizing the MHLC-C instrument was granted from the late Professor Kenneth A. Wallston. Minor alterations were done from the original version of the instrument (Wallston et al, 1994). In the present study, Cronbach's alpha coefficient for ILC was 0.62, for ELC-chance 0.86, for ELC-physician 0.61, and for ELC-other 0.58.

HADS

The third section assessed anxiety and depression using the Icelandic version of the Hospital Anxiety and Depression Scale (HADS) (Schaaber et al, 1990). HADS has been developed and tested for its reliability in studies on patients with cancer and chronic diseases showing Cronbach alpha range from 0.83-0.85 (Ágústsdóttir et al, 2010; Smári and Valtýsdóttir, 1997). HADS consist of 2 subscales assessing the level of anxiety (HADS-A) and symptoms of depression (HADS-D). Each subscale consists of seven items rated on a four-point Likert scale indicating symptoms during the past week. Each subscale has a possible score range of 0-21. A score of 0 to 7 for either scale is considered normal (no symptoms), a score of 8 to 10 suggests possible symptoms, and a score of 11 or higher indicates probable symptoms of either anxiety or depression for the respective subscale. The Cronbach alpha coefficient in our study for the HADS-A was 0.86 and 0.80 for the HADS-D.

MDASI

Lastly, the Icelandic version of the M. D. Anderson Symptom Inventory (MDASI) was used to assess the severity of symptoms and the interference with daily living caused by these symptoms. The MDASI is a useful tool to measure symptom prevalence, severity, and interference with daily life during the last 24 hours on a scale of 0-10 with 0 being "not present" and 10 being "as bad as you can imagine." It is well liked, easy to answer and brief

(13 items), and can easily be adapted for use with any medical or health related condition. It assesses both symptom severity (pain, fatigue/tiredness), nausea, disturbed sleep, being distressed, shortness of breath, difficulty remembering, lack of appetite, feeling drowsy, dry mouth, feeling sad, vomiting and numbness or tingling). It also measures how symptoms interfere with six aspects of the patient's daily functioning (daily activity, mood, work, relations with others, walking, and enjoyment of life) (Cleeland, 2016). MDASI has been proved to be a reliable instrument in studies in various countries (Jones et al, 2014; Hu et al, 2022; Viganò et al, 2021; Piil et al, 2020), showing Cronbach alpha range from 0.82 to 0.96. The Cronbach alpha coefficient in the present study was 0.92, 0.87 and 0.89 for the MDASI total, Interference and Symptom Severity scale, respectively. The internal consistency of the scales was established through the calculation of Cronbach alpha coefficient, with the range of values being between 0.00 and 1.00 (Altman, 1991).

Analysis

Data were analysed using the Statistical Package for the Social Science (SPSS 26.0) and the Statistical Software programme Jamovi 2.2. Descriptive statistics included description of sample mean, standard deviations (SD) and percentages. The data were not normally distributed, so a Mann-Whitney U-test was used to analyse significant differences between two groups in psychological distress, LOC, somatic symptoms, and its interference with daily life. Kruskal-Wallis test was used in case the groups were more than two. Mann-Whitney U-test with a reduced p-value was used as a post hoc test to prevent the risk of finding significant differences by chance (Type I error) (Pallant, 2016). Pearson r correlation coefficient was used to analyse significant correlation between psychological distress, LOC, somatic symptoms, and its interference with daily life on a scale varying from - 1 through 0 to + 1 (Altman, 1991). In our analysis we considered that according to Cleeland (2016), when calculating the subscale score on the MDSAI, seven of the 13 core symptoms severity items and four of the six interference items will represent the majority of the items for the subscales; thus, if the participant responded to fewer than half of the subscale's items, the subscale should be considered as "missing." Differences were taken as statistically significant with a p-value of <0.05 (Cronbach, 1951).

Results

The response rate was 80% (N=247), with higher number of women (57.1%) than men (42.9%); most participants (32%) were in the age group 61 to 70 years old; most of them were married or cohabiting (77.7%); high school diploma was the most reported education (44.5%), while 34.8% had a university degree. Being diagnosed once was reported by the majority (72.5%), and 66.1% said that the reason for treatment was cure. Radiotherapy and chemotherapy were distributed almost equally among participants (Table 1).

Comparison of mean scores

Women scored higher on the anxiety scale than men. The age group <50 had significantly higher anxiety than the other age groups ($p < 0.001$). Participants who belonged to the age group 61-70 years old reported significantly higher scores for faith in ELC-physicians than those who were in the age group <50 ($p < 0.001$). Those who were in treatment for symptom control only, reported significantly higher scores for MDASI total than those in treatment aiming for cure ($p < 0.001$); for them interference with daily life was also found to be significantly worse ($p < 0.001$). Chemotherapy treatment had significantly the most impact on total scores for MDASI total ($p < 0.001$), symptoms severities ($p < 0.001$), and interference with daily life ($p < 0.001$), compared to those receiving radiotherapy or a combination of both (Table 2).

Correlation between variables

Significant positive relationship was observed for HADS (anxiety) with HADS (depression) ($r = 0.56$, $p < 0.01$), MDASI-Symptom severity ($r = 0.42$, $p < 0.01$), and MDASI-Interference scale ($r = 0.41$, $p < 0.01$). The same was found between HADS (depression) with ELC-others ($r = 0.17$, $p < 0.01$), MDASI-Symptom severity ($r = 0.54$, $p < 0.01$), and with the MDASI-

Interference scale ($r=0.63$, $p<0.01$). A significant positive relationship was observed for ILC and ELC-chance ($r=0.39$, $p<0.01$), ELC-physician ($r=0.18$, $p<0.01$), and with ELC-others ($r=0.20$, $p<0.01$). The same was found between ELC-chance and ELC-physician ($r=0.21$, $p<0.01$), ELC-chance and ELC-others ($r=0.36$, $p<0.01$), and ELC-physician and ELC-others ($r=0.22$, $p<0.01$). A significant positive relationship was also found for MDASI-Severity of symptoms with MDASI-Interference ($r=0.78$, $p<0.01$). A significant negative relationship was observed for HADS (anxiety) with ILC ($r=-0.21$, $p<0.01$), and for HADS (depression) and ILC ($r=-0.26$, $p<0.01$). The same results were shown for ILC and MDASI-Severity of symptoms ($r=-0.18$, $p<0.01$), and for ILC with MDASI-Interference ($r=-0.23$, $p<0.01$) (Table 3).

Discussion

The purpose of the present study was to determine HLC, anxiety and depression levels in patients with cancer during the time of chemotherapy or radiotherapy treatment. A further aim was to assess the severity of somatic symptoms and their interference with patients' daily life. It has been suggested that a person's health and health behaviour are important factors when people are challenged with any medical or health related condition (Goldzweig et al, 2016; Kulpa et al, 2014), characterized and controlled by two forces which have been described earlier as ILC and ELC, the latter encompassing three subscales (having faith in doctors, having faith in other people, and believing in chance and fate) (Wallston et al, 1994).

This dichotomization is prominent in the HLC literature (Wallston et al, 1994; Keinki et al, 2016; Lopez-Carrido, 2020). As has been mentioned earlier, individuals with an ILC are characterized by greater self-activity including self-control of their own life believing that the probability of success depends on their own efforts, their high aspirations and faith in their own strengths. On the contrary, individuals with ELC do not trust themselves and do not believe in the effectiveness of their own actions, therefore, they submit to others (Sacha and Gibek, 2019). Results from this study indicate that men and women do not differ regarding internal reinforcement (ILC), nor was there a difference between gender in external reinforcement (ELC) (Wallston et al, 1994). This contradicts findings in Sacha and

Gibek's (2019) and Dopelt et al's (2022) studies on patients with cancer showing women demonstrate more external control than men, but notably only in the chance factor.

Zeilinger et al (2022) note that the prevalence of anxiety and depression is high in patients with cancer, and the most frequent comorbidities, although this is still unclear. In their study on outpatients with cancer it was found that every sixth patient was likely to have a psychiatric condition, with women being more frequently affected. These results are in accordance with numerous previous findings in studies on outpatients with cancer who found that being a woman was an important factor for both anxiety and depression (Hjörleifsdóttir et al, 2006; Hjörleifsdóttir et al, 2007; Yüce et al, 2021). The present study indicates that women may be more anxious than men, and the severity of symptoms and their interference with daily life may have more impact on women than men. These findings were not significant, but they should, however, not be overlooked. Rather, they call for further investigations to identify underlying causes for distress and experience of symptom burden amongst patients with cancer (Table 2).

It is also important to highlight the psychological distress reported by the younger patients with cancer. Results are consistent with findings in previous studies conducted on outpatients with cancer (Hjörleifsdóttir et al, 2007; Krok et al, 2013) indicating that the youngest ones, 50 years old and younger, are significantly the most vulnerable when in the situation of having cancer and receiving treatment. These findings indicate that the older generations have less psychological distress than younger patients with cancer. This does not necessarily mean that having cancer and receiving treatment affects the older individuals any less than it does the younger persons, it does, however, indicate different reasons for psychological distress related to different situations and responsibilities in life. In this context, it is noteworthy that the age groups 70 years old and older were those who reported significantly strongest belief in ELC-chance and those 61-70 had significantly strongest belief in ELC-physician (Table 2).

The results did not allow for a division between the consequences of the cancer and the side effects of treatment. Yet, the results give reason to believe that treatment given for symptom control only, the severity of symptoms and their interference with patients' daily life are significantly worse than amongst those who are receiving treatment for curing the disease. A significant difference in severity of symptoms between types of treatment was

also found, since patients receiving chemotherapy reported higher scores of severity of symptoms and their interference with patients' daily life than those having radiotherapy or a combination of both. This may be, to some extent, related to the side effects of radiotherapy being known to appear later in the treatment process than in chemotherapy (Table 2). These findings correlate with previous findings on side effects of cancer treatment (Pearse and Haas, 2017; Prieto-Callejero et al, 2020).

It is interesting that findings in this present study indicate that boundaries between ILC, ELC and its subscales, can be diverse and a clear distinction is not necessarily the case. Results showed a positive significant correlation between all the three subscales of ELC (belief in chance, physicians, and others) and ILC. This is in accordance with Rotter (1975) who emphasized that this should be conceptualized as a continuum between ELC and ILC, rather than it being an either/or categorization. Wallston and Wallston's (1978) argue that in a situation of cancer, only low internal control may be possible, thus, patients are more dependent on external sources of control, such as doctors or others. Boddu et al (2021) also suggest that individuals can have both internal and external locus at the same time and the concept of internality and externality cannot be dichotomized.

The present study found that there was a positive significant correlation between believing in physicians and believing in others (Table 3), but this should not come as a surprise, insofar as these two categories are intertwined (Wallston et al, 1994; Boddu et al, 2021). Adding to the above, O'Bryan (2021) argued that human agency consists in being able to decide your actions and reactions. If the reasons are part of your own psychology, we talk about ILC, if the reasons originate in the views of knowledge, power or actions of others, we talk about ELC. These two types of loci of control do not exclude each other, and it depends on the context which one is appropriate insofar as trusting and believing in your doctor because he or she has the knowledge to possibly cure your sickness does not necessarily decrease one's ILC. Sacha and Gibek (2019) suggest that the longer is the disease process for the patient, the stronger is the belief that his own health is a result of the actions of others. Findings in this present study are in accordance with previous studies, indicating that the lower is the degree of anxiety and depression, the higher is the degree of ILC (Kulpa et al, 2014). Additionally, findings in this present study are in line with previous findings on patients with cancer (Zhang et al, 2015; Sacha and Gibek, 2019) indicating that the longer the disease persists in oncological patients, the weaker is their ILC, and their

sense of responsibility for the process weakens as well.

Limitations

The primary limitation of this study is the relatively small sample size. Other factors which may be seen as possible limitations of categorisation may be the lack of information on the type of cancer, the duration of the disease, and that patients were receiving different treatments at various phases in their disease process. Furthermore, data collection, including reason for treatment and stage of disease, was solely built on information from the patients themselves and was not checked against patients' medical files. To some extent, this may limit the accuracy of the information, but results give valuable insight into how the patients perceive their own situation and how they describe it. With respect to information revealing similar percentage between the numbers reporting treatment for curing the disease (62.3%) and those with local cancer (62.8%), and between the numbers reporting treatment for symptom control (32%) and those with metastatic disease (35.6%), there is reason to believe that this information is close to reality. It is, however, not possible to jump to any conclusion on whether this was exactly the right division between these two groups or not; it does, however, provide information on a very difficult and sensitive experience seen from patients' perspectives. In this context, cancer patients are increasingly having treatment for a longer time where the goal is to relieve symptoms and prolong life but not to cure (Ho et al, 2011; Randén et al, 2013). Despite these limitations, the findings in the present study are similar to reports in larger studies in terms of HLC, psychological distress and somatic symptoms (Krok et al, 2013; Zeilinger et al, 2022).

Conclusion

The results of this study provide insights into different aspects of HLC among outpatients with cancer who are receiving chemotherapy or radiotherapy. Findings indicate that ILC may alleviate psychosocial suffering and make the life of the patient more bearable. There is reason to consider the difference between genders in future studies on this matter, because

women were found to be more anxious than men and they were suffering more from physical symptoms. The results of this study call for increased attention to the younger patients with cancer, indicating that the youngest ones, 50 years old and younger, are the most vulnerable when in the situation of having cancer and receiving treatment. This does not necessarily mean that having cancer and receiving treatment affects the older individuals any less than it does the younger persons; it does, however, tell us to consider different reasons for psychological distress related to different situations and responsibilities in life. In this context, it is noteworthy that the age groups 70 years old and older were those who reported significantly strongest belief in ELC-chance and those 61-70 had significantly strongest belief in ELC-physician. The results may suggest that the longer the disease persists, the more severe impact it has on a patient's psychosocial well-being and the more it interferes with their daily life.

Findings in this study distinguish between ILC and ELC and the authors suggest that ILC may be more appropriate and helpful to master the cognitive perception of the threat of illness than ELC. Additionally, Marton et al (2021) found that people with a lower score in ELC (having faith in other people), were more likely to prefer an active role or collaborative role in medical decision-making. The authors suggest that it may be so that people do not fully grasp the impact that other people and doctors could have on their health. Studies have revealed that cancer patients with a higher ELC are significantly more often using sources of information as well as being significantly more in need for additional information than those with ILC (Keinki et al, 2016). The authors suggest that by measuring HLC amongst patients with cancer would be helpful to make a more useful plan for the patients regarding support and care. The HLC-C questionnaire is short and easy to answer, and it is simple to use in outpatient clinics where patients come for their treatment. Often the patients' greatest fear is to lose control over their lives. It is, therefore, urgent to understand patients' fear and anxiety, and help them to encounter this new reality and to master the cognitive perception of the threat of illness. One way to do so is by measuring their inner strength and work from there to assist them in building up inner strength to be able to handle the situation.

Acknowledgement

We want to thank late Professor Kenneth A. Wallston, Vanderbilt Kennedy Center, USA, for his assistance in obtaining permissions for translating the MHLC-C questionnaire into Icelandic and using it in this study. We also want to thank the staff at the [University of Texas, MD Anderson Cancer Center](#) for their permissions for translating the M.D. Anderson Symptom Inventory (MDASI) into Icelandic and use it in this study. The authors would like to express their gratitude to all the participants who contributed valuable information.

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