

Cancer Association of South Africa (CANSA)



Fact Sheet on Cancer Survivorship

Introduction

The term 'cancer survivor' means different things to different people. For some, the term refers to anyone who has been diagnosed with cancer; others consider a cancer survivor to be anyone who has completed active treatment and is free of any signs of disease.

[Picture Credit: Survivor]



The Cancer Association of South Africa (CANSA) defines a 'cancer survivor' as any person who has been told that he/she has cancer and remains a cancer survivor until he/she dies of whatever cause.

At the end of active treatment, many survivors often have mixed emotions, including relief that their treatment is over, as well as anxiety about the future. After treatment, the 'safety net' of regular, frequent contact with the health care team ends. Some survivors may miss this source of support, especially because anxieties may surface at this time. Others may have physical problems, psychological problems, sexual problems, and fertility concerns. Many survivors feel guilty about surviving, having lost friends or loved ones to the disease. Some survivors are uncertain about their future, while others experience discrimination at work or find that their social network feels inadequate.

Phases of Cancer Survivorship

According to the MD Anderson Cancer Center, cancer survivorship has three distinct phases, namely: living with, through, and beyond cancer.

Living with cancer - refers to the experience of receiving a cancer diagnosis and any treatment that may follow. During this time:

- Survivors will undergo treatment and/or may be asked to join a clinical trial to study new cancer therapies.

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- Survivors and their caregivers may be offered services to help cope with emotional, psychological and financial concerns.

Living through cancer - is the period following treatment in which the risk of cancer recurring is relatively high. Many survivors are relieved that treatment is over, but anxious about no longer seeing their cancer doctor on a regular basis.

During this stage:

- Survivors typically see their cancer doctor two to four times a year depending on their circumstances.

Living beyond cancer - refers to post-treatment and long-term survivorship. While two out of three survivors say their lives returned to normal, one-third reported continuing physical, psychosocial or financial consequences.

During this stage:

- Most survivors go back to the care of their primary physician
- Ideally, survivors will have developed a long-term health care plan with their cancer doctor to be implemented by their primary physician

More and more people every day are surviving cancer. The following are some of the survivorship issues that affect cancer survivors:

Incidence of Cancer in South Africa

According to the outdated National Cancer Registry (2017), known for under reporting, the following number of cancer cases was histologically diagnosed in South Africa during 2017:

Group - Males 2017	Actual No of Cases	Estimated Lifetime Risk
All males	39 975	1:6
Asian males	980	1:7
Black males	13 166	1:9
Coloured males	4 734	1:5
White males	21 095	1:3

Group - Females 2017	Actual No of Cases	Estimated Lifetime Risk
All females	41 670	1:8
Asian females	1 300	1:7
Black females	18 814	1:10
Coloured females	4 575	1:7
White females	16 981	1:4

The frequency of histologically diagnosed cases of cancer in South Africa for 2017 was as follows (National Cancer Registry, 2017):

Group - Males 2017	0 – 19 Years	20 – 29 Years	30 – 39 Years	40 – 49 Years	50 – 59 Years	60 – 69 Years	70 – 79 Years	80+ Years
All males	526	672	1 968	3 919	7 240	11 705	9 320	3 615
Asian males	8	33	47	88	185	336	226	57
Black males	395	399	1 164	1 877	3 107	3 692	1 925	598
Coloured males	45	60	183	448	1 103	1 444	1 062	389
White males	78	180	574	1 506	3 855	6 224	6 107	2 571

Group - Females 2017	0 – 19 Years	20 – 29 Years	30 – 39 Years	40 – 49 Years	50 – 59 Years	60 – 69 Years	70 – 79 Years	80+ Years
All females	474	1 092	4 218	7 167	8 636	9 176	7 210	3 697
Asian females	16	33	103	230	308	320	218	72
Black females	353	768	2 975	4 225	4 149	3 382	2 061	901
Coloured females	34	89	319	740	1 053	1 165	802	373
White females	70	202	821	1 972	3 126	4 309	4 129	2 351

N.B. In the event that the totals in any of the above tables do not tally, this may be the result of uncertainties as to the age, race or sex of the individual. The totals for 'all males' and 'all females', however, always reflect the correct totals.

Possible Side Effects of Cancer Treatment

Not everyone experiences side-effects in the same way. Side-effects depend on:

- the part of the body being treated
- the type of treatment given, e.g. radiotherapy, chemotherapy, hormone therapy, targeted therapy, biologic therapy, immunotherapy, etcetera

Most effects that survivors may experience are normal. The treating doctor or professional nurse will be in a position to inform survivors of what can be expected from a particular treatment.

Herrmann, J. 2020.

“Remarkable progress has been made in the development of new therapies for cancer, dramatically changing the landscape of treatment approaches for several malignancies and continuing to increase patient survival. Accordingly, adverse effects of cancer therapies that interfere with the continuation of best-possible care, induce life-threatening risks or lead to long-term morbidity are gaining increasing importance. Cardiovascular toxic effects of cancer therapeutics and radiation therapy are the epitome of such concerns, and proper knowledge, interpretation and management are needed and have to be placed within the context of the overall care of individual patients with cancer. Furthermore, the cardiotoxicity spectrum has broadened to include myocarditis with immune checkpoint inhibitors and cardiac dysfunction in the setting of cytokine release syndrome with chimeric antigen receptor T cell therapy. An increase in the incidence of arrhythmias related to inflammation such as atrial fibrillation can also be expected, in addition to the broadening set of cancer therapeutics that can induce prolongation of the corrected QT interval. Therefore, cardiologists of today have to be familiar not only with the cardiotoxicity associated with traditional cancer therapies, such as anthracycline, trastuzumab or radiation therapy, but even more so with an ever-increasing repertoire of therapeutics. This Review provides this information, summarizing the latest developments at the juncture of cardiology, oncology and haematology.”

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Vromans, R.D., Pauws, S.C., Bol, N., van de Poll-Franse, L.V. & Krahmer, E.J. 2020.

Background: The increased availability of patient reported outcome data makes it feasible to provide patients tailored risk information of cancer treatment side effects. However, it is unclear how such information influences patients' risk interpretations compared to generic population-based risks, and which message format should be used to communicate such individualized statistics.

Methods: A web-based experiment was conducted in which participants (n = 141) read a hypothetical treatment decision-making scenario about four side effect risks of adjuvant chemotherapy for advanced colon cancer. Participants were cancer patients or survivors who were recruited from an online Dutch cancer patient panel. All participants received two tailored risks (of which the reference class was based on their age, gender and tumor stage) and two generic risks conveying the likelihood of experiencing the side effects. The risks were presented either in words-only ('common' and 'very common'), or in a combination of words and corresponding numerical estimates ('common, 10 out of 100' and 'very common, 40 out of 100'). Participants' estimation of the probability, accuracy of their estimation, and perceived likelihood of occurrence were primary outcomes. Perceived personal relevance and perceived uncertainty were secondary outcomes.

Results: Tailored risks were estimated as higher and less accurate than generic risks, but only when they were presented in words; Such differences were not found in the verbal and numerical combined condition. Although tailoring risks did not impact participants' perceived likelihood of occurrence, tailored risks were perceived as more personally relevant than generic risks in both message formats. Finally, tailored risks were perceived as less uncertain than generic risks, but only in the verbal-only condition.

Conclusions: Considering current interest in the use of personalized decision aids for improving shared decision-making in oncology, it is important that clinicians consider how tailored risks of treatment side effects should be communicated to patients. We recommend both clinicians who communicate probability information during consultations, and decision aid developers, that verbal descriptors of tailored risks should be supported by numerical estimates of risks levels, to avoid overestimation of risks.

Please refer to the following two (2) Fact Sheets for information:

- Fact Sheet on Chemotherapy
- Fact Sheet on Radiation Therapy

Both these Fact Sheets are available on the CANSA website at www.cansa.org.za

Other Fact Sheets that are available on the CANSA Website on specific types of cancer should also be consulted. They can be viewed at www.cansa.org.za

Treating Cancer Pain

Up to 5 in 10 people who have treatment for cancer (50%) have some pain. When cancer has come back or spread, about 7 in 10 people (70%) have pain. If one has pain, it is important to tell one's doctor and nurse so they can treat it.

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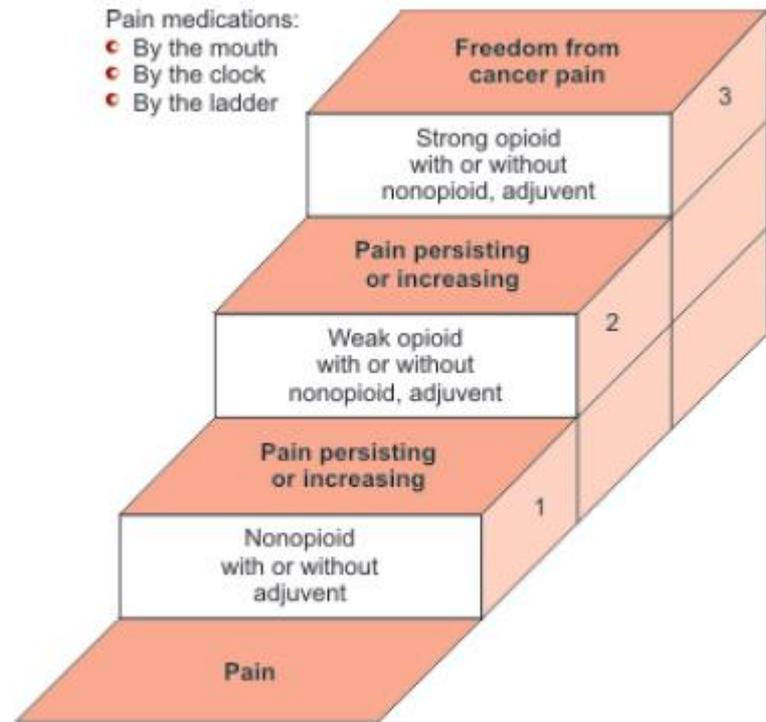
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Some people may not want to talk about their pain as they feel they are complaining. But the earlier treatment is given for pain, the more effective it is.

The way people feel and experience pain varies. Even people with the same type of cancer can have very different experiences.

[Picture Credit: WHO Pain Relief Ladder]

The amount of pain one has is not necessarily related to how severe the cancer is. Having pain does not always mean that the cancer is advanced or more serious. Pain does not always get worse as the cancer develops. It is important to remember that cancer pain can almost always be reduced.



Pain is an uncomfortable, unpleasant physical sensation as well as an emotional experience. It happens when parts of the body are damaged. This damage irritates nerve endings, which then send a warning signal to the brain. The brain responds by making one feel pain or discomfort.

Pain is not only a physical sensation. Emotions can make the pain better or worse. If one is anxious, one may feel more pain, and if one is relaxed, one may feel less pain. Persons suffering from cancer pain should not hesitate to consult a medical practitioner about their cancer pain and treatment thereof.

There are individuals who claim that recent advances in the availability of medicinal marijuana has greatly increased the capacity to effectively treat severe cancer pain that does not respond to traditional treatment. However, marijuana is still illegal in South Africa and medicinal marijuana is still not legally available locally.

Boland, E.G., Bennett, M.I., Allgar, V. & Boland, J.W. 2020.

Objectives: There is increased interest in cannabinoids for cancer pain management and legislative changes are in progress in many countries. This study aims to determine the beneficial and adverse effects of cannabis/cannabinoids compared with placebo/other active agents for the treatment of cancer-related pain in adults.

Methods: Systematic review and meta-analysis to identify randomised controlled trials of cannabinoids compared with placebo/other active agents for the treatment of cancer-related pain in adults to determine the effect on pain intensity (primary outcome) and adverse effects, including dropouts. Searches included Embase, MEDLINE, PsycINFO, Web of Science, ClinicalTrials.gov, Cochrane and grey literature. Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines were followed.

Results: We identified 2805 unique records, of which six randomised controlled trials were included in this systematic review (n=1460 participants). Five studies were included in the meta-analysis (1442 participants). All had a low risk of bias. There was no difference between cannabinoids and placebo for the difference in the change in average Numeric Rating Scale pain scores (mean difference -0.21 (-0.48 to 0.07, p=0.14)); this remained when only phase III studies were meta-analysed: mean difference -0.02 (-0.21 to 0.16, p=0.80). Cannabinoids had a higher risk of adverse events when compared with placebo, especially somnolence (OR 2.69 (1.54 to 4.71), p<0.001) and dizziness (OR 1.58 (0.99 to 2.51), p=0.05). No treatment-related deaths were reported. Dropouts and mortality rates were high.

Conclusions: Studies with a low risk of bias showed that for adults with advanced cancer, the addition of cannabinoids to opioids did not reduce cancer pain.

Cognitive Changes Following Cancer Treatment

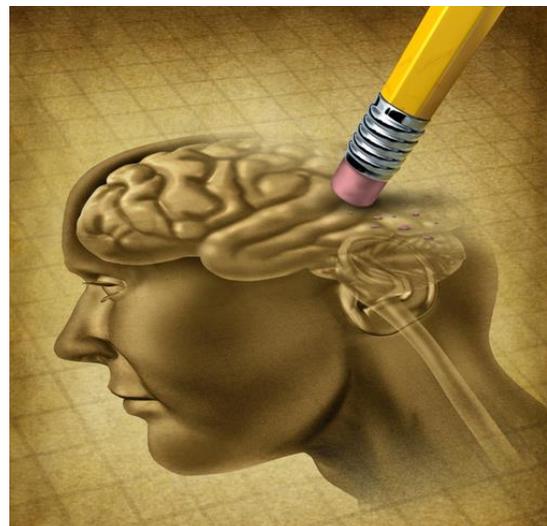
'Chemo brain' is a common term used by cancer survivors to describe thinking and memory problems that can occur after cancer treatment. Chemo brain can also be called chemo fog, chemotherapy-related cognitive impairment or cognitive dysfunction.

Though chemo brain is a widely used term, it is misleading. It is still not altogether clear that chemotherapy is the sole cause of concentration and memory problems in cancer survivors.

Despite the many questions, it is clear that the memory problems commonly called chemo brain can be a frustrating and debilitating side effect of cancer and its treatment. More study is needed to understand this condition.

Signs and symptoms of chemo brain may include:

- Being unusually disorganised
- Confusion
- Difficulty concentrating
- Difficulty finding the right word
- Difficulty learning new skills
- Difficulty multitasking
- Fatigue
- Feeling of mental foginess
- Short attention span
- Short-term memory problems
- Taking longer than usual to complete routine tasks
- Trouble with verbal memory, such as remembering a conversation
- Trouble with visual memory, such as recalling an image or list of words



[Picture Credit: Chemo Brain]

It is still not altogether clear what causes signs and symptoms of memory problems in cancer survivors.

Cancer-related causes could include:

- Cancer treatments
 - Chemotherapy
 - Hormone therapy

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- Immunotherapy
 - Radiation therapy
 - Stem cell transplant
 - Surgery
- Complications of cancer treatment may include
 - Anaemia
 - Fatigue
 - Infection
 - Menopause (associated with hormone therapy)
 - Nutritional deficiencies
 - Sleep problems, such as insomnia
 - Emotional reactions to cancer diagnosis and treatment
 - Anxiety
 - Depression
 - Other causes
 - Inherited susceptibility to chemo brain
 - Medications for other cancer-related signs and symptoms, such as pain medications

When to see a doctor - If a cancer survivor experiences troubling memory or thinking problems, he/she must make an appointment with his/her doctor. Keep a journal of signs and symptoms so that the doctor can better understand how memory problems are affecting everyday life.

No standard treatment has been developed for cancer-related memory problems. Because symptoms and severity differ from person to person, one's doctor can work with one to develop an individualised approach to coping.

Petrykey, K., Lippé, S., Robaey, P., Sultan, S., Laniel, J., Drouin, S., Bertout, L., Beaulieu, P., St-Onge, P., Boulet-Craig, A., Rezgui, A., Yasui, Y., Sapkota, Y., Krull, K.R., Hudson, M.M., Laverdière, C., Sinnett, D. & Krajinovic, M. 2019.

BACKGROUND: A substantial number of survivors of childhood acute lymphoblastic leukemia suffer from treatment-related late adverse effects including neurocognitive impairment. While multiple studies have described neurocognitive outcomes in childhood acute lymphoblastic leukemia (ALL) survivors, relatively few have investigated their association with individual genetic constitution.

METHODS: To further address this issue, genetic variants located in 99 genes relevant to the effects of anticancer drugs and in 360 genes implicated in nervous system function and predicted to affect protein function, were pooled from whole exome sequencing data of childhood ALL survivors (PETALE cohort) and analyzed for an association with neurocognitive complications, as well as with anxiety and depression. Variants that sustained correction for multiple testing were genotyped in entire cohort (n = 236) and analyzed with same outcomes.

RESULTS: Common variants in MTR, PPARA, ABCC3, CALML5, CACNB2 and PCDHB10 genes were associated with deficits in neurocognitive tests performance, whereas a variant in SLCO1B1 and EPHA5 genes was associated with anxiety and depression. Majority of associations were modulated by intensity of treatment. Associated variants were further analyzed in an independent SJLIFE cohort of 545 ALL survivors. Two variants, rs1805087 in methionine synthase, MTR and rs58225473 in voltage-dependent calcium channel protein encoding gene, CACNB2 are of particular interest, since associations of borderline significance were found in replication cohort and remain significant in

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combined discovery and replication groups (OR = 1.5, 95% CI, 1-2.3; p = 0.04 and; OR = 3.7, 95% CI, 1.25-11; p = 0.01, respectively). Variant rs4149056 in SLCO1B1 gene also deserves further attention since previously shown to affect methotrexate clearance and short-term toxicity in ALL patients.

CONCLUSIONS: Current findings can help understanding of the influence of genetic component on long-term neurocognitive impairment. Further studies are needed to confirm whether identified variants may be useful in identifying survivors at increased risk of these complications.

Controlling other causes of memory problems - cancer and cancer treatment can lead to other conditions, such as anaemia, depression, sleep problems and early menopause, which can contribute to memory problems. Controlling these other factors may make it easier to cope with these symptoms.

Learning to adapt and cope with memory changes - a neuropsychologist, who specialises in diagnosing and treating conditions that affect memory and thinking, can create a plan to help one cope with chemo brain symptoms. Doctors sometimes refer to this as cognitive rehabilitation or cognitive remediation.

Learning to adapt and cope with memory changes may involve:

Repetitive exercises to train one's brain - memory and thinking exercises may help the brain repair broken circuits that may contribute to chemo brain.

Tracking and understanding what influences memory problems - carefully tracking memory problems may reveal ways to cope. For instance, if one tends to become more easily distracted when hungry or tired, one could schedule difficult tasks that require extra concentration for the time of day when one feels at one's best.

Learning coping strategies - one may learn new ways of doing everyday tasks to help one concentrate. For instance, one may learn to take notes or make an outline of written material as one reads. Or a therapist may help one to learn ways of speaking that helps one commit conversations to memory and then retrieve those memories later.

Stress-relief techniques - stressful situations can make memory problems more likely. And having memory problems can be stressful. To end the cycle, one may learn relaxation techniques. These techniques, such as progressive muscle relaxation, may help one identify stress and help one cope.

Medications - no medications have been approved to treat chemo brain. But medications approved for other conditions may be considered.

Medications that are sometimes used in people with these symptoms include:

- Methylphenidate (Concerta, Ritalin, others), a drug used to treat attention-deficit/hyperactivity disorder (ADHD)
- Donepezil (Aricept), a drug used in people with Alzheimer's disease
- Modafinil (Provigil), a drug used in people with certain sleep disorders

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More study is needed to understand how, or if, these drugs may be helpful for people with these types of memory problems.

Avoid Risky Behaviours

Avoid risky behaviours that can lead to infections that, in turn, may increase the risk of cancer.

For example:

- Practice safe sex. Limit the number of sexual partners, and use a condom when having sex. The more sexual partners, the more likely one is to contract a sexually transmitted infection — such as Human Immunodeficiency Virus (HIV) or Human Papilloma Virus (HPV). People who have HIV or Acquired Immune Deficiency Syndrome (AIDS) have a higher risk for cancer of the anus, cervix, lung and immune system. HPV is most often associated with cervical cancer, but it may also increase the risk for cancer of the anus, penis, throat, vulva and vagina.



[Picture Credit: Condom]

- Do not share needles with anyone. Sharing needles with other persons can lead to HIV, as well as hepatitis B and hepatitis C — which can increase the risk of liver cancer (Mayo Clinic).

Spirituality

Religious and spiritual values are important to people who are coping with cancer. Spirituality may be defined as an individual's sense of peace, purpose and connection to others, as well as beliefs on the meaning of life. This may be found and expressed through an organised religion or in other ways.

[Picture Credit: Prayer]



Research shows that things such as positive beliefs, comfort and strength gained from religion, meditation and prayer can contribute to healing and a sense of well-being. Improving one's spiritual health may not cure an illness, but it may help one feel better, prevent some health problems and help one cope with illness, stress or death.

Ferrell, B., Chung, V., Koczywas, M., Borneman, T., Irish, T.L., Ruel, N.H., Azad, N.S., Cooper, R.S. & Smith, T.J. 2020.

Objectives: Patients with cancer who are at a transition to Phase I investigational treatments have been identified as an underserved population with regard to palliative care. This disease transition is often accompanied by spiritual and existential concerns. The study objective was to conduct a

secondary analysis of data from a larger study testing a palliative care intervention. This paper reports the findings of this secondary focus on the spiritual needs of this population.

Methods: Patients (n = 479) were accrued to this study prior to initiating a Phase I clinical trial with data collected at baseline, and 4, 12, and 24 week follow-up.

Results: Qualitative data revealed that the transition to Phase 1 trial participation is a time of balancing hope for extended life with the reality of advancing disease. Quantitative results demonstrated increased spirituality over time in both religious- and non-religious-affiliated patients.

Conclusions: Patients entering Phase I trials have important spiritual needs as they face treatment decisions, advancing disease, and often mortality. Spiritual care should be provided to seriously ill patients as a component of quality care.

Dos Reis, L.B.M., Leles, C.R. & Freire, M.D.C.M. 2020.

Objectives: To investigate associations between religiosity, spirituality and quality of life (QoL) in patients with visible sequelae due to head and neck cancer surgery.

Subject and methods: Cross-sectional study in 202 patients in a cancer hospital in Brazil. Psychosocial, demographic and clinical conditions were collected through interviews, clinical examinations and from the medical records. The outcome was QoL, measured by the Functional Assessment of Cancer Therapy-Head and Neck (FACT-HN) and the University of Washington QoL Questionnaire for patients with head and neck cancer (UW-QOL). The explanatory variables were religiosity (Duke University Religiosity Index-DUREL) and spirituality (Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale-FACIT-Sp12). Pearson's correlation and linear regression were used for data analysis.

Results: Religiosity and spirituality were associated with both measures of the patients' QoL. After adjustment, higher scores of QoL (FACT-HN and UW-QOL) were found in patients with higher levels of religiosity and of spirituality. Other significant covariates were gender (male), those living with their families, with sequelae not involving the cervical region, longer post-surgical time and who had no chemotherapy or radiation.

Conclusion: Religiosity and spirituality were associated with the patients' QoL, regardless of their sociodemographic and cancer-related clinical conditions and behaviours.

Sprick, P.J., Tata, B., Kelly, B. & Fitchett, G. 2020.

“Research conducted over the last 20 years supports that many patients with cancer engage religion and spirituality (R/S) when coping with their illness. Research on patients with brain cancer is more minimal but mirrors the same findings. This article provides a brief overview of the research about R/S and coping among cancer patients, then summarizes the research about R/S among patients with brain cancer and their caregivers. The following topics are discussed: (I) the importance of R/S to patients with brain cancer and their caregivers, (II) specific R/S needs experienced by patients with brain cancer and their caregivers over the cancer continuum, (III) R/S coping mechanisms engaged by brain cancer patients and their caregivers, and (IV) the healthcare systems' engagement of R/S needs within the healthcare setting. This is followed by professional chaplains' descriptions of their own experience with R/S concerns of patients with brain cancer and their caregivers, and the spiritual care they have offered them. Hear My Voice, a new spiritual life review intervention, is described. Research to deepen understanding of the R/S concerns of patients with brain cancer and their loved ones, and spiritual care interventions offered to them is recommended.”

Balducci, L. 2019.

“Cancer is a major cause of morbidity and mortality for older individuals. Palliative care is essential to improve the outcome of cancer treatment in terms of quality of life and treatment satisfaction. This review examines the influence of spirituality on aging in general and on the management of older cancer patients. A spiritual perspective has been associated with successful aging, and with better

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tolerance of physical and emotional stress, including the ability to cope with serious diseases and with isolation. It has also been associated with decreased risk of suicide and depression. Gerotranscendence, the more urgent search for meaning by older than younger individuals, confirms the importance of spirituality in this phase of life. Spirituality has also improved the quality of life and reduced the risk of disease and death for the patient's caregiver. Addressing patient and caregiver spirituality may render the palliative care of cancer more effective and may also aid in detection and management of spiritual pain, which may prevent healing at the end of life.”

Emotional and Mental Health

The following may assist in maintaining a balance as far as emotional and mental health is concerned:

- *Build confidence* – identify abilities and weaknesses together, accept them and build on them. Do the best with what is available
- *Make time for family and friends* - these relationships need to be nurtured. If taken for granted family and friends will not be there to share life's joys and sorrows
- *Give and accept support* - friends and family relationships thrive when they are 'put to the test'
- *Manage stress* - all may have stressors in their lives but learning how to deal with them when they threaten to overwhelm one may maintain one's mental health
- *Find strength in numbers* - sharing a problem with others who have had similar experiences may help find a solution and may make one feel less isolated



[Picture Credit: Mental Health]

- *Identify and deal with moods* - all need to find safe and constructive ways to express one's feelings of anger, sadness, joy and fear
- *Learn to be at peace with yourself* - get to know who you are, what makes you really happy, and learn to balance what you can and cannot change about yourself (Canadian Mental Health Association)
- *Volunteer* - being involved in one's community may give one a sense of purpose and satisfaction that paid work cannot. Become a CANSA Volunteer. Contact CANSA on the toll free number 0800 22 66 22 or visit the CANSA Website www.cansa.org.za

Wang, Y., Duan, Z., Ma, Z., Mao, Y., Li, X., Wilson, A., Qin, H., Ou, J., Peng, K., Zhou, F., Li, C., Liu, Z. Chen, R. 2020.

“The current study aimed to explore mental health problems in patients diagnosed with cancer during the COVID-19 pandemic. A cluster sampling, cross-sectional survey with 6213 cancer patients was conducted in one of the largest cancer centers in China. The socio-demographic and clinical characteristics, psychosomatic conditions, interpersonal relationships and social support, COVID-19 infection-related psychological stress, and mental health status were measured. Medical conditions

were extracted from patients' electronic healthcare records. Among the 6213 cancer patients, 23.4% had depression, 17.7% had anxiety, 9.3% had PTSD, and 13.5% had hostility. Hierarchical linear regression models showed that having a history of mental disorder, excessive alcohol consumption, having a higher frequency of worrying about cancer management due to COVID-19, having a higher frequency feeling of overwhelming psychological pressure from COVID-19, and having a higher level of fatigue and pain were the predominant risk factors for mental health problems in cancer patients. However, there were only 1.6% of them were seeking psychological counseling during COVID-19. We also revealed the protective factors associated with lower risk of mental health problems among cancer patients. The present study revealed a high prevalence of mental health problems and gaps in mental health services for cancer patients, which also indicated high distress from COVID-19-elevated risks. We call for systematic screening of mental health status for all cancer patients, and developing specific psychological interventions for this vulnerable population.”

For additional information, please refer to the following Fact Sheet that is available on the CANSA Website at www.cansa.org.za:

- Fact Sheet on Cancer and Mental Health.

Granek, L., Nakash, O., Ariad, S., Shapira, S. & Ben-David, M.A. 2019.

OBJECTIVES: To explore oncologists, social workers and nurses' perceptions about the causes of their cancer patient's mental healthdistress.

METHODS: The Grounded Theory Method (GT) of data collection and analysis was used. Sixty-one oncology healthcare professionals were interviewed about what they perceived to be the causes of mental health distress in their patients. Analysis involved line-by-line coding, and was inductive, with codes and categories emerging from participants' narratives.

RESULTS: Oncology healthcare professionals were sensitive in their perceptions of their patients' distress. The findings were organized into three categories that included disease related factors, social factors, and existential factors. Disease related themes included side effects of the disease and treatment, loss of bodily functions, and body image concerns as causing patient's mental health distress. Social related themes included socio-economic stress, loneliness/lack of social support, and family related distress. Existential themes included dependence/fear of being a burden, death anxiety, and grief and loss.

CONCLUSIONS: Oncology healthcare professionals were able to name a wide range of causes of mental health distress in their patients. These findings highlight the need to have explicit conversations with patients about their mental status as well as explore their understanding of their suffering. A patient centered approach that values the patient's conceptualization of their problem and their narrative to understanding their illness can improve the patient- provider relationship and facilitate discussions about patient centered treatments.

Depression

Depression is a disorder characterised by feeling down, depressed, or sad - having little interest or receiving little pleasure in doing things, and feeling hopeless. These feelings often persist for two or more weeks and negatively affect a person's daily activities or relationships. The symptoms of depression may appear shortly after diagnosis or anytime during or after treatment.

People are more likely to experience depression during or after cancer if they have been diagnosed with depression in the past, have close family members with depression, have significant anxiety and worry, are facing cancer alone or without the support of friends or family, or have financial burdens.

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Although depression is more common among people with cancer, it should not be considered a normal part of living with cancer. Depression lowers a person's quality of life, undermining the emotional and physical strength often required to undergo cancer treatment. It may also interfere with a person's ability to make choices about cancer treatments. Identifying and then managing depression are important parts of coping with cancer.

For additional information, please refer to the following Fact Sheet that is available on the CANSA Website at www.cansa.org.za:

- Fact Sheet on Cancer and Mental Health.

Bamonti, P.M., Moye, J. & Naik, A.D. 2018.

“Depression is common but under-diagnosed in cancer survivors. This study characterized depressive symptoms over one year in cancer survivors and examined disease-related and psychosocial predictors of depression severity. Participants (n = 122; M_{age} 65.33, SD = 9.17, 98.4% male) with head and neck, esophageal, gastric, or colorectal cancers were recruited through tumor registries at two regional Veterans Administration Medical Centers. Self-report measures assessing depressive symptoms (PHQ-9), combat-related PTSD symptoms (PC-PTSD), and health-related quality of life (PROMIS) were administered at six, twelve, and eighteen months after diagnosis. Symptoms consistent with major depression were endorsed by approximately one-quarter of the sample at six (24%), twelve (22%), and eighteen (26%) months post diagnosis, with 12% of participants reporting consistently significant depressive symptoms. In multivariate modeling, significant predictors of depression at eighteen months included prior depressive symptoms ($\beta = .446, p < 0.001$) and current pain interference ($\beta = .231, p = .003$). The present findings suggest that major depression is common and persistent one year following cancer diagnosis. Attention to pain management and routine monitoring of mood symptoms is critical to reducing risk of depression in cancer survivors.”

Returning to Work

Once one's cancer treatment is complete or nearing completion and one has been cleared to return to work, at least part-time, more challenges may await. After using up medical leave, gear up for the next challenge: making a re-entry to working life as comfortable as possible.

[Picture Credit: Returning to Work]



For many cancer survivors, thinking about returning to work often brings mixed emotions: relief, trepidation, hope - and perhaps awkwardness. Even if one is sure of being ready to return, there may still be some worries: Will there be scepticism or support?

Here are some suggestions for smoothing the transition from cancer patient back to being a valued employee and cancer survivor:

- It is important to test one's psyche - just as important as feeling capable of doing the job is feeling psychologically up to speed. If feeling below par, it may be advisable to seek one-on-

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one counselling from a social worker or a therapist, or to join a support group of other cancer survivors returning to work

- Evaluate readiness to work – is there an intention to return full-time or part-time? If part-time sounds more feasible, consider what accommodations may be needed. Do mornings work better, or afternoons? Take into account any medications and their possible side effects
- Attend workshops or seminars to refresh skills
- Attend industry events to keep knowledge up-to-date
- Focus on the work itself, even if catching up means tending to tedious tasks such as returning a boatload of telephone calls or tackling a mountain of mail. It is important to resume routine

Fertility

Chemotherapy, radiation, and surgery all can have lasting effects on reproductive health. Risk depends on the diagnosis, the type of treatment, and the dose of treatment - higher doses are more likely to lead to infertility. Even an experienced doctor cannot accurately predict with 100% certainty what the lasting effects may be.

It is crucial to discuss matters around fertility with a health professional before any cancer treatment is commenced with. Aspects to include in the discussions:

- In vitro fertilisation
- Ovarian tissue freezing
- Embryo banking
- Freezing and storing sperm

In general:

- Some chemotherapy drugs are more likely to lead to infertility than others. The high-risk drugs most likely to affect reproductive organs are Cytoxan (known generically as cyclophosphamide), Ifosfamide, Procarbazine, Busulfan, and Melphalan. Others, like vincristine and methotrexate, are typically less likely to harm fertility. Some of these drugs also may interrupt menstruation in girls and/or cause early menopause.



[Picture Credit: Fertility]

- Radiation treatments can damage testes or ovaries. If radiation is focused on or near the pelvic area, abdomen, spine, and/or the whole body, it may cause damage to sperm or eggs. Also, radiation to the abdomen, pelvic area, or entire body may affect a girl's uterine function and cause difficulty in carrying a baby to full term. It also can interrupt menstruation in girls or reduce sperm count and motility in boys - these conditions may be permanent or may reverse after the treatment. Children who have radiation to certain areas of the brain also may have their fertility affected.

- If the cancer involves the reproductive organs, surgery might be recommended and doctors might need to remove part of the reproductive organs to remove the cancer.

Dellino, M., Minoia, C., Paradiso, A.V., De Palo, R. & Silvestris, E. 2020.

“The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), also identified as Corona virus disease 19 (COVID-19), has recently produced a dramatic and widespread sanitary emergency. However, despite the necessity to assist a substantial number of affected patients, it is also essential to, at the same time, guarantee the usual clinical care, particularly to cancer patients, including fertility preservation (FP) strategies before the beginning of the anti-cancer treatments. The FP techniques for adult female patients include oocyte and embryo cryopreservation, which require both adequate ovarian reserve (OR) and controlled ovarian stimulation (COS) to promote multiple follicular growth. However, ovarian tissue cryopreservation is an additional FP practice suitable when an anti-cancer treatment is urgently required, whereas, for male patients, sperm cryopreservation is a simple and well-adopted procedure. Here, we focus on the current conditions in terms of agreements and rules of FP procedures during this COVID-19 pandemic to achieve and provide useful recommendations for the adoption of these techniques in patients with cancer.”

Stukenborg, J-N. & Wyns, C. 2020.

“Genetic parenthood following cancer therapy is considered to be a major factor of quality of life. Given the rising proportion of patients surviving cancer due to improved therapeutic protocols, it is an issue of growing importance. Hence, the efforts to preserve fertility have motivated researchers to develop options for the paediatric population facing fertility-threatening cancer therapies. In prepubertal boys who do not yet produce sperm, cryo-banking of testicular tissue containing spermatogonial stem cells (SSCs) is the only viable option for future fertility preservation. While proposed in a number of clinics worldwide, however, this strategy remains still experimental. Transplanting the SSCs, or testicular tissue containing SSCs, back to the cured patient appears the most promising strategy. However, experiments performed with human testicular tissue in mice models reveal spermatogonial loss after transplantation, indicating the need for further optimisation of the transplantation procedure. The approach further poses the risk of reintroducing tumour cells back to the patient. In cases of haematological and blood-metastasising malignancies, *in vitro* generation of sperm combined with assisted reproductive technologies (ART), is the only possibility, avoiding reintroducing cancer cells. Although xenotransplantation would allow to recover sperm cells for ART being thus on the safe side with regard to cancer cells, the risk of infections with xeno-microbiological agents makes this option incompatible with clinical application. So far, offspring from *in vitro* matured sperm has only been achieved in mice. While human haploid germ cells, showing specific morphological features, expression of post-meiotic markers, as well as DNA and chromosome content, as well as fertilisation and development capacity, have been obtained by culturing spermatogonia or immature testicular tissue, the functionality of these cells still needs to be demonstrated. Despite the promising results obtained in recent years, further research is urgently warranted to establish a clinical tool offering these boys a fertility restoration option in the future. This mini-review will focus on current achievements and future challenges of fertility preservation in young boys and underscore the next steps required to translate experimental strategies into clinical practice.”

Lokich, E. 2019.

Survivorship care includes surveillance and prevention of cancer recurrence, addressing side effects of cancer and cancer treatment and coordination of follow-up care. This article reviews guidelines for surveillance of women with ovarian, endometrial, cervical, and vulvar cancer. It also reviews many of the long-term physical side effects of gynecologic cancer treatment including fatigue, neuropathy, lymphedema, cognitive dysfunction, sexual health concerns, menopausal symptoms, infertility, and

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economic stressors. Finally, survivorship care plans are reviewed as a tool for coordinating care for women with a history of gynecologic cancer.

Del-Pozo-LRIDA, s., Salvador, C., Martinez-Soler, F., Tortosa, A., Perucho, M., Gimnez-Bonaf, P. 2019. "Survival rates in oncological patients have been steadily increasing in recent years due to the greater effectiveness of novel oncological treatments, such as radio- and chemotherapy. However, these treatments impair the reproductive ability of patients, and may cause premature ovarian failure in females and azoospermia in males. Fertility preservation in both female and male oncological patients is nowadays possible and should be integrated as part of the oncological healthcare. The main objective of this review was to describe the different existing options of fertility preservation in patients undergoing gonadotoxic cancer treatments, as well as the differences in success rates that may appear in the different techniques evaluated. Emerging techniques are promising, such as the cryopreservation in orthotopic models of ovarian or testicle tissues, artificial ovaries, or in vitro culture prior to the autotransplantation of cryopreserved tissues. However, oocyte vitrification for female patients and sperm banking for male patients are considered the first line fertility preservation option at the present time for cancer patients undergoing treatment. Certainly, new fertility preservation techniques will continue to develop in the following years. However, despite the growing advances in the subject, optimal counselling from healthcare professionals should always be present."

Improving Quality of Life

The following actions may be helpful in improving quality of life:



[Picture Credit: Quality of Life]

- Take one day and make one decision at a time - try to focus on only resolving today's problems. Avoid projecting worst-case scenarios for the future. Taking one small step at a time can help one feel less vulnerable and give one a greater sense of control.
- Accept that some things may be out of one's control - focus on those things that can be controlled and take action on those instead.
- Ask for support - be open with family and friends about feelings and how they can be of support. Offer specific examples, such as: being driven to appointments, researching sources for financial support, or just listening. It is also good practice to take someone with to medical appointments to take notes and help one remember instructions and information.
- Communicate with the whole healthcare team - prepare a list of questions for each appointment. If something is not understood, ask for clarification. Ask to see X-rays or scans to get a better picture of what is going on. If there are problems to develop a good relationship with a particular doctor, consider finding another. In general, it is useful to get a second opinion on one's diagnosis and treatment to feel more confident about next steps.
- Retain as much control of one's life as is reasonable - having cancer can make it difficult for one to feel in charge of one's life and care. Work with the doctor, nurse, and caregiver to

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develop a plan that gives as much control over one's own life as desired and comfortably handled.

- Acknowledge and express one's feelings - a diagnosis of cancer can trigger many strong emotions. Take time to listen to yourself. Find constructive ways to express feelings through writing, talking, physical activity or creative pursuits. Consider professional support when there is a feeling that depression or anxiety may hamper the ability to function well.
- Seek support from other cancer survivors - people often find a sense of comfort when they communicate with others affected by cancer. Contact the Cancer Association of South Africa (CANSA) or ask the treating doctor, nurse, or social worker about local support groups.
- Set aside 30 minutes every day for self — discover new ways to bring happiness and contentment into every day.
- Learn relaxation techniques – 'relaxation' refers to a calm, controlled physical state that enhances one's well-being. Relaxation is something that one might have to learn, or build it into every day. This is important to do. Consider music that makes one happy, reading a book, or taking a walk. Yoga, tai-chi, or meditation programmes may also be helpful. Take time to enjoy every moment.
- Do only what is enjoyable - try to find humour in the unexpected moments of each day. Consider activities that can be enjoyed and that can be done comfortably. If there is a need to spend time alone, allow yourself exactly that.
- Be open to one's own emotions — don't be afraid to feel both negative and positive emotions.
- Take action to reduce stressors — chronic stress will not help the situation. Explore relaxation and stress relief strategies such as exercise, Tai Chi, yoga, meditation or expressive writing or art.
- Make healthy lifestyle choices – it is never too late to make changes that will absolutely improve one's well-being. Improving one's diet, including exercise, and maintaining intimacy are all ways of feeling better both physically and emotionally.
- Try something new - maybe starting a herb garden, growing orchids, taking a cooking class or learning to dance.
- Maintain a spirit of hope - hope is desirable and reasonable. Even if one's cancer journey is complicated, one can still set small goals and enjoy daily pleasures. It may be necessary to redefine how, and when, hope is experienced by focusing on one's own spiritual beliefs, cultural customs, and family connections.

Find a new 'normal' - the idea is to find a new 'normal' and embrace it. Do not look back, but remember what brought happiness and recognise any new limitations.

Crossnohere, N.L., Richardson, D.R., Reinhart, C., O'Donoghue, B., Love, S.M., Smith, B.D. & Bridges, J.F. 2019.

Objective: Acute myeloid leukemia (AML) is experiencing a therapeutic renaissance due to the heightened biomedical understanding of AML and patient-focused drug development (PFDD). Many AML patients now live long-term with the side effects of treatment. This study documents the prevalence and severity of AML treatment-related side effects.

Methods: A national cross-sectional survey designed with the Leukemia & Lymphoma Society assessed patients' experiences with short-term (nausea/vomiting, diarrhea, hair loss, mouth sores, infection, rash) and long-term (organ dysfunction, chemobrain, fatigue, neuropathy) treatment side effects. Patient and caregiver participants rated sideeffect severity (none-severe).

Results: Survey participants (N = 1182) were mostly female (65%), AML patients (76%), and had undergone chemotherapy (94%). Eighty-seven percent of participants reported severe short-term effects, and 33% reported severe long-term effects of treatment. Only 11% of respondents did not have any severe effects. Hair loss and fatigue were the most common severe short- and long-term side effects (78%, 33%). There was a moderate correlation between having short- and long-term adverse effects ($r = 0.41$, $P < 0.001$). Caregivers were more likely than patients to report severe organ dysfunction, fatigue, & neuropathy (P -values < 0.05).

Conclusions: Survivors experience a high burden of side effects from AML treatments highlighting the need for the development of less toxic therapies. Differences in patients' and caregivers' experiences illustrate the importance of sampling from diverse sources to understand the full burden of AML treatment, and the need for less toxic drugs. This study informs patients, patient-advocacy groups, clinicians, and regulators about AML treatment burdens and provides the community with information to inform PFDD.

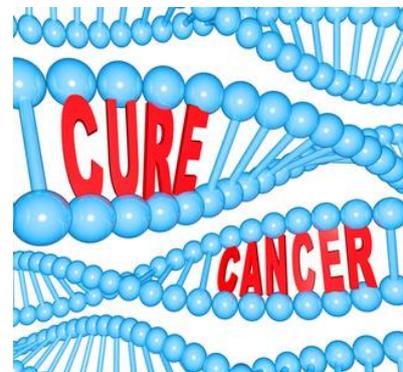
Understanding Recurrence

It can be extremely difficult to live with the fact that one's cancer may come back. Even if told by doctors that they are 95% certain the cancer has gone for good, it may be very upsetting that no one can say "Yes, the cancer is cured". Some people find they cannot stop thinking about having had cancer, even though they expected to put it behind them once their treatment had finished. Many individuals may feel a little frightened of planning anything in the future or may feel sad or depressed.

For most people who are in this situation, each day lowers the risk of a recurrence. Most cancers that are going to come back will do so in the first two years after treatment. After five years one is even less likely to get a recurrence. For some cancers, after 10 years the doctor may say that such an individual is finally and totally in remission!

[Picture Credit: Recurrence vs Cure]

Unfortunately, some types of cancer can come back many years after they were first diagnosed. If someone finds it hard to get over having had cancer he/she may find it helpful to talk to other people in the same situation or to a trained counsellor. This can help him/her to find ways of dealing with the fear and worry. It may be helpful to contact the nearest CANSA office where information or counselling is offered.



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Cancer may come back some time after its initial treatment. This idea can be frightening. There are a number of different explanations for why cancer might come back.

The main reasons are that some cancer cells may have:

- been left in the body where the original cancer was
- spread to other parts of the body and gradually grown to form a new tumour

Cancer can come back after surgery because:

- there were cancer cells left behind during the operation
- some cancer cells had broken away from the primary cancer before the operation and spread to elsewhere in the body

Surgeons do their best to make sure that all the primary cancer is removed. But no medical scan has been invented that can pick up one cell, or small groups of cells that have spread. Most surgeons can provide an educated guess about whether the cancer is likely to have been cured by surgery. Adjuvant treatment can also be given to try to kill any cells that may have escaped.

Cancer cells are killed by chemotherapy drugs because these drugs attack cells that are in the process of doubling to form two new cells. Cells that are actively dividing are also more vulnerable to radiation, although it is not fully understood why this is - so radiotherapy works by killing dividing cells too.

Not all the cells in a cancer will be dividing at the same time. Normal cells go into a long rest period between divisions. Cancer cells do too, although the rest period may be much shorter. Giving chemotherapy and radiotherapy in a series of treatments helps to catch as many cells dividing as possible and so kill them. Hopefully, cells that were resting during the first treatment will be active during the next treatment and so will be more likely to die.

It is unlikely that any cancer treatment will kill every single cancer cell in one's body. To do that, the treatment would have to be very strong and would have too many dangerous side effects. What doctors are trying to do is to reduce the numbers of cancer cells to the extent that there are too few cells left for the cancer to survive. They hope the remaining cells will be killed off by the body's own defences - or will just die off naturally, as many cancer cells do when they leave the primary tumour.

Treating doctors will want to give each patient as much treatment as they can. But they cannot give more than what is safe. All treatments have a safe limit. One can only have up to a certain amount of radiotherapy to any particular part of the body. If one has more, then normal body tissue will be too damaged to repair itself.

Chemotherapy drugs have their limits too. Some can cause problems with the heart, liver, lungs or kidneys, so the dosage has to be carefully calculated.

Cure or Remission?

These days many cancers are cured. But some cancers can come back many years after they have first been treated. So, one may find that doctors are very unwilling to use the word 'cure' even though there is no sign that there is any of the cancer left. The cancer will be said to be in 'remission'. This means there is no sign of cancer left in the body.

If there are any cancer cells left:

- there are too few to find
- there are too few to cause any symptoms
- the cells may be in an inactive state
- the cells are not growing
- the cells are not multiplying out of control

Many patients may be on some type of long-term treatment to try to keep any remaining cancer cells in an inactive state - for example, hormonal therapy for breast cancer. Being on this type of long-term treatment does not mean that the cancer is definitely still there.

When Cancer Does not Go Away – What Then?

Adults and children react differently when informed that their cancer or the cancer of someone they love will not go away or has recurred.

How adults may react

- If told that the cancer is advanced, an adult may suddenly confront challenging emotional issues and the possibility of death. He/she might feel strong emotions, such as fear, anger, guilt, loneliness or denial.
- Many people say that the news of advanced cancer is more devastating than the original diagnosis. Anxiety and depression are common and it can be harder to cope emotionally.
- The person may be worried about the impact of the cancer on his/her family. Some people avoid talking about the advanced cancer because they do not know what to say. However, people with advanced cancer who express their emotions and communicate with family and friends may find it easier to cope.
- For some people, faith and spiritual beliefs can help them get through tough times. For others, cancer can test their beliefs. Either way, every individual may find it helpful to talk to a spiritual adviser.

How children may react

- If the cancer has advanced, it is important to keep talking with the affected child. Again, just as with the diagnosis, children may sense that something is happening, and not telling them can add to their anxiety and distress.
- How a child may react to a diagnosis of advanced cancer can affect how the whole family adjusts. If the affected child is anxious and depressed, the family may be too.
- Some studies of children with advanced cancer show that family members often feel more distressed than the child affected by cancer. This seems to be more common where there is a lack of communication.
- When children find out that the cancer is advanced, they may have similar but more intense reactions than when they found out about the original diagnosis. They are likely to feel insecure, although teenagers may not want their loved ones to see this. Depending on their age, children usually have different immediate concerns when they hear the news.

What to tell children of cancer survivors

Preparing children for the loss of a parent, brother or sister, or someone very close to them, is an incredibly hard thing to do. The following is a guide on how to approach the initial conversation.

Be honest and open - once children know the cancer has advanced, they will need to be given some kind of an idea about what this may mean, in terms of the outcome (prognosis). With some cancers, the prognosis is fairly clear and people will know that they may only have months to live. However, more and more people with advanced disease are surviving for a longer time, sometimes for many years.

If death is likely in the short term, it is best to be as honest as one can be. If one needs to talk about oneself or one's partner, this can be an especially hard thing to do. One does not need to do it on one's own: social workers and other health professionals at the cancer treatment centre or the palliative care service can help one tell one's children.

Being open about death gives the survivor as well as the family the chance to show and say how much they care for each other, as well as the opportunity to work on unresolved issues. The chance to talk through old arguments and make amends seems to be particularly important for older children.

Use words they can understand - terms such as 'passed away', 'passed on', 'lost', 'went to sleep', 'gone away' or 'resting' can be confusing for children. It is usually best to use straightforward language. This includes using the words 'dying' or 'death'.

Tell them what to expect - prepare children by explaining how the illness might affect the patient in the days ahead. For example, the patient might be sleepy or need a lot of medicine.

Wait for the child to ask - give brief answers to questions they ask. It usually does not help to offer lots of explanations if the child is not ready to hear them.

[Picture Credit: Beads of Hope Canada]



Balance hope with reality - parents worry that if they talk about the death they take away their children's hope. One can still be honest and offer hope. Tell the children how the person with cancer is being cared for – the treatment he/she is having, what the doctors say, and what things can be put in place to make things easier for the family.

Organ Donation Following a Cancer Diagnosis

There are cancer survivors who want to help other people by becoming organ donors. For many people who have had cancer, it is possible to donate - but this varies by cancer type and medical condition.

There is always a pressing need for donated organs. Some organ donations, such as kidney donation, may be done when a person is still living. Others are possible only if a person wishing to donate passes away under certain circumstances.

Can a donated organ give someone cancer?

The risk of passing on cancer to the person who gets an organ is very small, but there have been some reports in the medical literature of this happening. This is partly because organ recipients are given drugs to suppress their immune systems to help prevent rejection of the transplant. This may make their immune system unable to identify and kill cancer cells that may have been transplanted with the organ.

According to a study by the United Network for Organ Sharing (UNOS) in the United States of America, under certain circumstances there may be an acceptable risk in using organs from donors who have had certain types of cancer. This is particularly true if there is a long cancer-free interval before the organ donation. At present, UNOS does not recommend accepting organs from people with 'actively spreading cancer'. The exception to this is organs from donors with primary brain tumours that have not spread beyond the brain stem. These have not been found to impact life expectancy when compared to people who received organs from donors without brain cancer. In a study of nearly 500 organ recipients, no one got the disease from the donated tissue of a person who had brain cancer. Acceptance of organs for donation is up to each organ procurement agency and the organ recipient.

Some people with cancer may not qualify to be living donors due to their medical condition. That is, they may not be able to donate a kidney or a lobe of their liver, however, some may still have organs and body tissues that can be used after they pass away.



[Picture Credit: Organ Donor]

If someone wants to donate, it is fine to be listed as a donor. One must make sure that the rest of the family knows of these wishes, since they may be asked to give consent. If the cancer has been actively spreading, internal organs will not be taken, but if the person dies after being cancer-free for a long time, the organs may be used. Other tissues, such as skin, tendons, and bone can often be used. Careful testing of the organs and tissues is done at the time of death. The

decision about which organs or tissues can be safely used is then made by medical professionals, as long the family agrees that the person wanted to donate.

Even if other organs and tissues cannot be used, donating the corneas from the eyes is one way to offer help to others. Almost all people with cancer (except those with certain blood or eye cancers) can donate their corneas. Contact the tissue bank for more information in this regard.

Darlington, A-S., Long-Sutehall, T., Randall, D., Wakefield, C., Robinson, V. & Brierley, J. 2019.

Objective: A proportion of children die, making them potentially eligible to be organ/tissue donors. Not all are approached for donation, and experiences of those parents are not well understood. The objective was to investigate to what extent organ and tissue donation (OTD) is discussed as part of end-of-life care and to explore parents' and healthcare professionals' (HCPs) experiences.

Design: A retrospective qualitative study.

Setting: Multicentre study with participants recruited through two neonatal intensive care units (ICUs), two paediatric ICUs, a cardiac ICU and a children's hospice.

Patients: Bereaved parents, parents of a child with a long-term condition (LTC) and HCPs.

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Interventions: None.

Main outcomes and measures: Parents' and HCPs' views and experiences of discussions about OTD.

Results: 24 parents of 20 children were interviewed: 21 bereaved parents and 3 parents of a child with a LTC. Seven parents were asked about donation (13 not asked), four agreed and two donated. 41 HCPs were interviewed. Themes: complexity of donation process, OTD as a coping strategy, the importance of asking, difficulty of raising the topic, and parents' assumptions about health of organs (when donation is not discussed).

Conclusions: The findings add new knowledge about parents' assumptions about the value of their child's organs when discussions about OTD are not raised, and that HCPs do not routinely ask, are sometimes hesitant to ask in fear of damaging relationships, and the reality of the complexity of the donation process. Given the current levels of awareness around OTD, the topic should be raised.

Cancer and Sexuality

In addition to cancer survivors being human beings, all are also sexual beings! Sexuality is a normal, healthy, natural part of who humans are as individuals throughout every stage their lives. It is not one defined thing, but a combination of many aspects of one's life. Human sexuality includes not only sexual behaviour but also gender. It also includes how the human body works, values, attitudes, beliefs and feelings about life and love.

Youth learn about their sexuality from the day they are born. It is important to let kids feel good about their sexuality from the beginning. This will make it easier for them to ask questions about sex later on in life. Parents can initiate conversations about sexuality using many different themes - relationships, communication, respect, body image as well as intimacy and sexual behaviour - as a way to share values and factual information enabling young people to take charge of their lives, have loving relationships and make healthier, safer and better-informed decisions related to sexuality.

The term 'sex', in a biological sense is male, female, or intersexed. Sexual behaviour usually involves touching oneself or another person in ways that stimulate sexual feelings and pleasure. Sexual behaviour includes many different ways of touching which can range from holding hands or massage to masturbation or vaginal or anal intercourse including oral sex.

Sexuality changes and grows throughout one's life. Sexuality includes sexual behaviours, sexual relationships, and intimacy; how individuals choose to express themselves as males and females (including the way they talk, dress, and relate to others); sexual orientation (heterosexual, homosexual, bisexual), values, beliefs and attitudes as it relates to being male and female; changes that individuals go through like puberty, pregnancy or menopause; and the choice of having children or not.

Cancer treatment can cause a variety of sexual changes. Even though the causes may be different – surgery, chemotherapy, hormone treatment or radiation – the resulting changes are often similar. Some patients experience changes in all phases of sexual response (desire, arousal, orgasm, resolution), while others experience none.

The most common sexual change for cancer patients is an overall loss of desire. For men, erection problems are also a common problem. For women, vaginal dryness and pain with sexual activity are frequent. Most men and women are still able to have an orgasm even if cancer treatment interferes

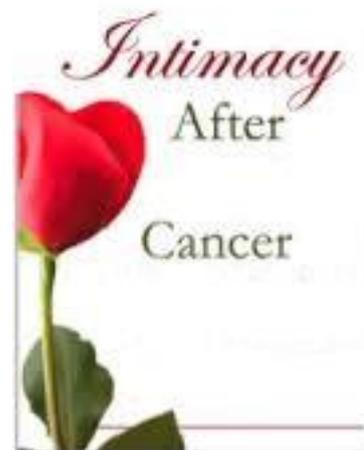
with erections or vaginal lubrication, or involves removing some parts of the pelvic organs. However, it is common for patients to need more time or stimulation to reach orgasm.

Cancer treatment side effects, such as fatigue, nausea, vomiting, diarrhoea, constipation, hair loss, weight changes, scars and sensitivity to tastes and smells may leave one feeling exhausted and uncomfortable. These side effects consume so much energy that sex may be low on the priority list at times. Although medications are available to treat many of these symptoms, some of these same drugs can decrease sexual desire or make it harder to reach orgasm.

[Picture Credit: Sexuality]

When sexual changes do occur, they generally do not improve right away, often persisting until a good remedy is found. Finding the most helpful remedy may take time and patience because sexual changes can be caused by both psychological and physical factors.

Furthermore, treatment-related sexual changes caused may be long-term or permanent. Survivors should talk with members of their health care team before treatment to learn about what sexual changes to expect from their cancer or cancer treatment. By knowing what may happen, one may be better prepared and more knowledgeable about potential sexual changes.



It is usually safe to have sex during cancer treatment unless the doctor tells one not to. Talk with the treating doctor before participating in sexual activities.

If one is having sex during chemotherapy, it may be advisable to use barrier protection, such as condoms or dental dams (for oral sex), since chemotherapy chemicals can be found in semen or vaginal fluid. More importantly for patients in their childbearing years a pregnancy, during or just after chemotherapy, can be complicated by birth defects.

Radiation therapy from an external machine does not make one radioactive or endanger one's partner in any way. If someone is undergoing brachytherapy, in which radioactive seeds are implanted in the body, he/she may have to stop sexual activity for a brief period until the strongest radiation has left the body.

Sex can be a problem if one has bleeding in the genital area or recently had surgery or if the immune system is very weakened.

Consultation with a sexologist may be of value in the event of any uncertainty about sex and sexuality.

Soanes, L. & White, I. 2018.

"There are many components affecting the experience of sexuality for adolescents and young adults living with and beyond cancer. For patients, the interruption to normal socialization creates gaps in information and experience that potentially hinder development. In clinical practice, conversations relating to sexual consequences of illness or treatment are rare, as are age-appropriate assessment and intervention. In service design, the collaborative approach of oncofertility has yet to be replicated for sexuality. This paper considers how these obstacles can be overcome through local service development to address unmet need and promote sexual well-being for this group of patients."

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Sexual Orientation and Cancer

While populations are often analysed by age, sex, and race with respect to cancer risk and cancer outcomes, sexual orientation has previously not been studied as a factor for either cancer incidence or cancer outcome. A study published in the journal *Cancer* on May 9, 2011 has now specifically examined the cancer survivorship of the gay, lesbian, and bisexual population (DOI: 10.1002/cncr.25950). The study authors found that cancer outcomes differ based on sexual orientation.

While there is a dearth of data on cancer survivorship among gay/lesbian/bisexual populations, it has been suggested that these populations generally engage in behaviours that are associated with greater cancer risk. These risk factors include a higher incidence of obesity and alcohol consumption among the lesbian population and a higher rate of smoking among gay men, lesbians, and bisexuals. Furthermore, recent studies have shown that same-sex sexual contact is linked to a higher incidence of head and neck and anal cancers. However, the question of cancer survivorship with respect to sexual orientation has not been well-studied, since most cancer surveillance studies do not record this statistic.

Lesbian, gay, and bisexual populations are not part of cancer surveillance, resulting in scarce information about the cancer survivorship of these populations. To address this information gap, the authors examined the prevalence of cancer survivorship by sexual orientation and cancer survivors' self-reported health by sexual orientation.

The authors explored these issues by analysing pooled data from the California Health Interview survey from 2001, 2003, and 2005. By using descriptive statistics and logistic regressions, they examined the cancer prevalence in men and women by sexual orientation and subsequently compared the self-reported health of male and female cancer survivors by sexual orientation.

Among women, the authors found no significant differences in cancer prevalence by sexual orientation, but lesbian and bisexual female cancer survivors had 2.0 and 2.3 × the odds of reporting fair or poor health compared with heterosexual female cancer survivors. Among men, they found significant differences in cancer prevalence, with gay men having 1.9 × the odds of reporting a cancer diagnosis compared with heterosexual men. There were no differences by sexual orientation in male cancer survivors' self-reported health.

There are sex differences in the impact of cancer on lesbian, gay, and bisexual cancer survivors. Lesbian and bisexual cancer survivors need to be targeted by programmes and services to assist these cancer survivors in improving their health perceptions, whereas healthcare providers and public health agencies need to be made aware of the higher prevalence of cancer in gay men to prevent future cancers through increased screening and primary prevention.

Lee, M., Jenkins, W.D. & Boakye, E.A. 2020.

Purpose: Although few studies have examined screening uptake among sexual minorities (lesbian, gay, bisexual, queer), almost none have examined it in the specific context of rural populations. Therefore, our objective was to assess how cancer screening utilization varies by residence and sexual orientation.

Methods: Publicly available population-level data from the 2014 and 2016 Behavioral Risk Factor Surveillance System were utilized. Study outcomes included recommended recent receipt of breast, cervical, and colorectal cancer screening. Independent variables of interest were residence (rural/urban) and sexual orientation (heterosexual/gay or lesbian/bisexual). Weighted proportions

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and multivariable logistic regressions were used to assess the association between the independent variables and the outcomes, adjusting for demographic, socioeconomic, and healthcare utilization factors.

Results: Rates for all three cancer screenings were lowest in rural areas and among sexual minority populations (cervical: rural lesbians at 64.8% vs. urban heterosexual at 84.6%; breast: rural lesbians at 66.8% vs. urban heterosexual at 80.0%; colorectal for males: rural bisexuals at 52.4% vs. urban bisexuals at 81.3%; and colorectal for females: rural heterosexuals at 67.2% vs. rural lesbians at 74.4%). In the multivariate analyses for colorectal screening, compared to urban heterosexual males, both rural gay and rural heterosexual males were less likely to receive screening (aOR = 0.45; 95% = 0.24-0.73 and aOR = 0.79; 95% = 0.72-0.87, respectively) as were rural heterosexual females (aOR = 0.87; 95% = 0.80-0.94) compared to urban heterosexual females. For cervical screening, lesbians were less likely to receive screening (aOR = 0.62; 95% = 0.41-0.94) than heterosexuals, and there were no differences for breast screening.

Conclusion: We found that rural sexual minorities may experience disparities in cancer screening utilization associated with the compounding barriers of rural residence and sexual minority status, after adjusting for demographic, socioeconomic, and healthcare utilization factors. Further work is needed to identify factors influencing these disparities and how they might be addressed.

Jabson, J.M. & Kamen, C.S. 2016.

“Satisfaction with care is important to cancer survivors' health outcomes. Satisfaction with care is not equal for all cancer survivors, and sexual minority (i.e., lesbian, gay, and bisexual) cancer survivors may experience poor satisfaction with care. Data were drawn from the 2010 LIVESTRONG national survey. The final sample included 207 sexual minority cancer survivors and 4,899 heterosexual cancer survivors. Satisfaction with care was compared by sexual orientation, and a Poisson regression model was computed to test the associations between sexual orientation and satisfaction with care, controlling for other relevant variables. Sexual minority cancer survivors had lower satisfaction with care than did heterosexual cancer survivors ($B = -0.12$, $SE = 0.04$, Wald $\chi(2) = 9.25$, $p < .002$), even controlling for demographic and clinical variables associated with care. Sexual minorities experience poorer satisfaction with care compared to heterosexual cancer survivors. Satisfaction with care is especially relevant to cancer survivorship in light of the cancer-related health disparities reported among sexual minority cancer survivors.”

Relay for Life

One person made a difference in 1985. One man decided he had to do something to stop the endless pain, suffering and loss due to cancer. He decided to raise funds for his local American Cancer Society, by doing something he enjoyed – running marathons. He spent an incredible 24 hours running around a track – a gruelling feat, but representative of what someone fighting cancer endures. He asked for the support of people he knew and raised US\$27 000.



[Picture Credit: Dr Gordy Klatt]

While Dr Klatt (a colorectal surgeon) circled the track, he thought about how others could take part. He envisaged a 24 hour team relay event that would raise money for the fight against cancer. Dr Gordy Klatt's determination was contagious and the following year he tapped into networks of friends, family and associates to celebrate cancer survivors and raise funds. Relay for Life was born. No longer just a

one-man show. Relay for Life events now involve entire communities with a mutual goal to celebrate cancer survivors and eradicate cancer.

South Africa too, embraced the concept of Relay for Life – with the Cancer Association of South Africa (CANSA) the South African licence holder. Relay for Life is a unique event that offers everyone in their respective community the opportunity to participate in the fight against cancer. It represents the HOPE that all of those lost to cancer will never be forgotten; that those who are fighting cancer will be supported and that one day cancer will be eliminated.

Relay For Life embraces entire communities; from the very young to the old. Teams raise funds before and during the Relay and these funds are dedicated to funding CANSA's unique, integrated service within various communities.



[Picture Credit: Relay for Life]

Participants enjoy camping-out, good entertainment, good food, games and community camaraderie. They all share a common purpose – celebrating cancer survivors and raising funds to eradicate cancer. Contact CANSA to join the next Relay for Life event in your area and come and celebrate your survivorship!

Reducing the Risk for Cancer by Living a Balanced Lifestyle

For more information on living a balanced lifestyle and thereby reducing the risk for cancer, please consult the following Fact Sheets that are available on CANSA's Website at www.cansa.org.za:

- Fact Sheet on Living a Balanced Lifestyle
- Fact Sheet on Dangers of Meats Cooked at High Temperatures
- Fact Sheet on Known Causes of Cancer
- Fact Sheet on Possible Harmful Chemicals in Personal Care Products

About Clinical Trials

Clinical trials are research studies that involve people. They are conducted under controlled conditions. Only about 10% of all drugs started in human clinical trials become an approved drug.

Clinical trials include:

- Trials to test effectiveness of new treatments
- Trials to test new ways of using current treatments
- Tests new interventions that may lower the risk of developing certain types of cancers
- Tests to find new ways of screening for cancer

The South African National Clinical Trials Register provides the public with updated information on clinical trials on human participants being conducted in South Africa. The Register provides information on the purpose of the clinical trial; who can participate, where the trial is located, and contact details.

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For additional information, please visit: www.sanctr.gov.za/

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This Fact Sheet is intended to provide general information only and, as such, should not be considered as a substitute for advice, medically or otherwise, covering any specific situation. Users should seek appropriate advice before taking or refraining from taking any action in reliance on any information contained in this Fact Sheet. So far as permissible by law, the Cancer Association of South Africa (CANSAs) does not accept any liability to any person (or his/her dependants/estate/heirs) relating to the use of any information contained in this Fact Sheet.

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Relay for Life

Prof Michael C Herbst. Picture taken at a Relay for Life Event held at the Denel Grounds in Irene, Pretoria, 2014.

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