

**CARING FOR THE CAREGIVERS-
WHAT WE NEED TO KNOW AND
DO**



CARING FOR THE CAREGIVERS

-Linda Montford (MSW/RSW)

I have no potential conflicts with this presentation.

WHAT WE KNOW ABOUT CANCER IS
THAT....

“Longer survival, increasing incidence, and a growing trend toward outpatient treatment have made family caregivers increasingly important in providing support and managing the care of patients with cancer.” (Kitrungrote and Cohen 2006)



WHAT ELSE WE KNOW...

Cancer has been referred to as a family disease, because it impacts everyone.

“Provision of cancer care is a unique and specific type of stress, which can be markedly different from caring for persons with other types of illnesses due in part to the perceived threat of mortality.” (Kim and Thomson, 2007).



WHAT WE ALSO KNOW....

CURRENT
ONCOLOGY
A Canadian Cancer Research Journal



Canadian Association of Psychosocial Oncology
Association Canadienne d'Oncologie Psychosociale

“Several studies*** have found that family members experience as much, if not more, distress as the patients. Family members typically experience fear of loneliness, a sense of helplessness, lifestyle disruption and uncertainty. Family members struggle with the possibility of death of their loved one, alternatively trying to avoid thoughts of death”. (CAPO, 2012)

THE CANCER TRAJECTORY



“Most studies examining the quality of life of caregivers have focused on their levels of anxiety and depression. Typically, higher levels of anxiety are reported in comparison to depression...”

These same researchers go on to say that,

“Borderline or clinical levels of anxiety appear to be more prevalent post-diagnosis or in the acute phase of the illness, however a certain percentage of caregivers continue...well into the medium and long-term survivor stage.”

(Girgis and Lambert 2009)



STAGE OF DIAGNOSIS



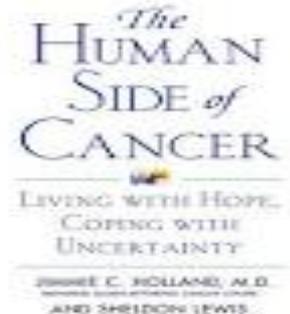
As would be expected, “...providing care to a relative whose cancer is more severe and whose mental and physical functioning is poor has been related to poorer QOL.” (Kim and Spillers 2009)

So, in general, stress or anxiety is greatest as the initial stage, but it increases as well with stage of cancer diagnosis. Health Care Providers then have to be careful of not overwhelming patients and caregivers at the beginning and provide realistic hope when at all possible.



BASED ON THE WORK OF JIMMIE HOLLAND...

- 3 stages of a cancer diagnosis:
 - 1. Denial and disbelief (Shock)
 - 2. Turmoil
 - 3. Adjustment –when treatment actually begins and there is relief that something is being done. (Accomodation)



WHO ARE THE CAREGIVERS?

-Anyone who provides physical/emotional care (Canadian Cancer Assoc.)

-partners, parents, children, siblings, friends.

“According to the Health Council of Canada, unpaid caregivers provide between 70-75% of care for people... In monetary terms, ...the economic contribution (for the elderly) is approximately \$26 billion per year”

(doctors of bc, 2016)





**BEFORE WE CONTINUE...A MOMENT
ABOUT WORDING**



“It is important to note that some caregivers do not regard themselves as caregivers or may dislike the label “caregiver” believing it can detract from their identity as a parent, child, partner, sibling, or friend...”

-Some people prefer the term “supporter” and some minimize their role if they are not providing physical care but “only emotional”.

(bc doctors)

Some people prefer no label at all.

KEY STATS

-54% are women

-15% of caregivers are young between the ages of 15-24

--28 % are “sandwiched” between caregiving and childrearing

-89% of caregivers do it for more than one year

(doctors of bc, 2016)



70% AND 67%

So, If caregivers are providing 70% of the care, we need to consider these individuals as vital team members.

“...after cancer survivors have been discharged from the hospital, it is primarily family members and close friends who assume responsibility...two thirds (67%) of cancer survivors have never used a community service to meet their daily instrumental needs.” (Kim et al. 2006)



70% AND 67%

SO, IF 70% OF THE CARE IS DONE BY FAMILY or FRIENDS AND 2/3RDS NEVER USE COMMUNITY SERVICES FOR INSTRUEMNTAL NEEDS,
WHAT IS THE TAKE HOME BOTTOM/LINE?

We need to support caregivers. We need to support the supporters.



**BUT ISN'T THIS THEIR JOB-TO LOOK
AFTER THEIR FAMILY?**

Absolutely, but families are very busy and complex these days....Approximately 40% of families end in divorce and 69% of families are dual income. (Stats Canada 2014)

It's our job then to at least check-in to see if families are getting the support they need.





BC DOCTORS, 4 STEPS TO CARE

THINK “IIMP”

1. IDENTIFY THE CAREGIVERS
2. INVOLVE CAREGIVERS IN PATIENT CARE
3. MONITOR THE HEALTH OF CAREGIVERS
4. PROVIDE INFORMATION AND SUPPORT TO CAREGIVERS
(bc doctors, “Organizing Your Practice to Support Family Caregivers- A toolkit for Doctors”)
And do this on an ongoing basis.

WHAT HEALTH CARE PROVIDERS CAN DO...

STEP 1. - IDNENTIFY THE CAREGIVERS.

This may not always be obvious. It could be friends, adult children, neighbours. Who is living in the home or providing support to the home is important to know.





ORGANIZE YOUR PRACTICE TO SUPPORT CAREGIVERS

According to “doctors of bc” it is not just up to the HCPs (Health Care Providers) to identify caregivers, but all staff including office assistants.

- For new patients, ask them- to identify any relatives or friends who provide care/support
- seek permission to give caregivers appropriate information about patient care and treatment
 - make note of information sharing agreements in patient notes
- ask caregivers to provide feedback on any difficulties they are having once a care plan is implemented



2. INVOLVE CAREGIVERS IN PATIENT CARE

Step 2- Involve Caregivers as “partners in patient care” . Talk to patients about information sharing and seek permission to give caregivers appropriate info.

If the patient doesn't want information shared, ensure that caregivers are provided general information on relevant health conditions (bc doctors, 2016)



AS PART OF INVOLVING FC, RECOGNIZE
THAT THERE IS A NATIONAL MOVE
TOWARDS CAREGIVERS AS PARTNERS



Few provinces in Canada have taken such a legislative or planning approach.

In 2011,

the Manitoba Government enacted the *Caregiver Recognition Act*, which
established

principles relating to caregivers and has outlined how caregivers should be
treated.(doctors of bc, 2016)



General Principles Relating to Caregivers

1. The relationship between caregivers and the persons for whom they care should be recognized and respected.
2. The valuable social and economic contribution that caregivers make to society should be recognized and supported.
3. Caregivers should be acknowledged as individuals with their own needs within and beyond the caring role.
4. Caregivers should be supported to enjoy optimum health and social well-being and to participate in family, social and community life.
5. Caregivers should be considered as important contributors with other care providers in the provision of care, support or assistance, acknowledging the unique knowledge and experience of caregivers.
6. Caregivers should be treated with dignity and respect.

**STEP 3. MONITOR THE HEALTH
OF CAREGIVERS...**



1. Being a caregiver/supporter can be stressful, how are you doing with all of this ?
 2. Are you taking breaks and getting out?
 3. Are you getting the support you need?"
4. Is there anything specific you would like to be able to talk about today? (If you sense extra support might be beneficial then add...)
- 5. "I often recommend people meet once with our Psychosocial Oncology Clinicians/Social Workers to find out what support and resources they provide. Would you be willing or interested to do this?"

Here are some similar questions recommended by JAMA (Journal of American Medical Assoc. 2015)

To provide the very best patient care, I find I need to also pay attention to my patients' caregivers. Can you tell me a bit about how you are feeling/doing?

Caregiving Can be stressful.

How are you coping with these responsibilities?

How would you describe your quality of life these days?

How often do you get out?

What do you do for fun?





Who gives you support? How helpful is this support?

We work with a social worker who is an expert in assisting caregivers.
May I refer you to this individual?

Caregiving is a very hard job and the best way to do it well is to take advantage of some of the resources available for help. Are you using any of these? May I help you with a referral?

NORMALIZE DON'T PATHOLOGIZE

While we don't want to pathologize families, we do want them to get the support they need. We want to empower them on this path.



**FORMAL ASSESSMENTS CAN BE
ADMINISTERED AS WELL**

Validated assessment tools include the Zarit Burden Interview ...
(bc doctors, 2016)



Short Form Zarit Burden Interview (ZBI-12)

	"Never" (0)	"Rarely" (1)	"Sometimes" (2)	"Quite frequently" (3)	"Nearly always" (4)
Do you feel...?					
That because of the time you spend with your relative that you don't have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

- Short form ZBI-12 validated as screening tool in advanced illness including dementia and cancer
- Total ZBI-12 score: summation of 12 items (0 to 4 points per item, total score range 0 to 48)
- Copyrighted, but available for free use by clinicians and for non-funded academic research
- Suggested guidelines for scoring:
 - 0-10: no to mild burden
 - 10-20: mild to moderate burden
 - >20: high burden

CAPO- has a self-administered survey for patients and caregivers in this booklet. If you sense extra support is needed, you can give this booklet to patients/supporters and they can take it home and do their own survey.

The Emotional Facts of Life with Cancer



A GUIDE TO COUNSELLING AND SUPPORT
FOR PATIENTS, FAMILIES AND FRIENDS

FOR FAMILY AND CAREGIVERS

The following questionnaire may help you as a family member or caregiver to determine whether you might benefit from professional counselling.

1. I feel anxious or worried about my loved one's cancer diagnosis/ treatment.

Not at all 1 2 3 4 5 All the time

2. I feel depressed or discouraged.

Not at all 1 2 3 4 5 All the time

3. I have been irritable or unusually angry and I have not

controlled it well.

Not at all 1 2 3 4 5 All the time

4. My sleeping habits have changed.

Not at all 1 2 3 4 5 Very much



5. *I have experienced a change in my appetite.*

Not at all 1 2 3 4 5 Very much

6. *I have had difficulty concentrating at work, home or school, or on routine things such as reading the newspaper or watching television.*

Not at all 1 2 3 4 5 Very much

7. *My loved one's diagnosis/ treatment interferes with my daily activities.*

Not at all 1 2 3 4 5 Very much

8. *My loved one's diagnosis/ treatment interferes with my family or social life.*

Not at all 1 2 3 4 5 Very much

9. *My loved one's diagnosis/ treatment interferes with sexual life.*

Not at all 1 2 3 4 5 Very much

10. *My loved one's diagnosis has caused financial hardship to our family.*

Not at all 1 2 3 4 5 Very much



11. I have difficulty keeping up with my caregiving activities.

Not at all 1 2 3 4 5 Very much

12. I have difficulty coping with the stress that the entire family is experiencing.

Not at all 1 2 3 4 5 Very much

Everyone experiences some of these symptoms, to varying degrees, part of the time. If you find that many of your answers are in columns four or five, and you are having difficulty dealing with your situation on your own, you may be experiencing significant distress. Please do not hesitate to discuss your feelings with a psychosocial oncology counsellor.

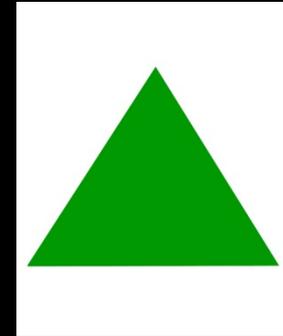
Based on tools developed by the Tom Baker Cancer Centre Department of Psychosocial Resources and Northwestern Ontario Regional Cancer Centre Supportive Care Program, with permission (partly derived from the Functional Living Index: Cancer and from the EORTC Core Quality of Life Questionnaire).



WHEN MEETING WITH PATIENTS
& SUPPORTERS, THINK GOOD
COMMUNICATION & TRIADS....

-Research shows that effective care with patients with cancer (and other life threatening illness) is “inextricably bound with and dependent upon effective communication.” (Washington et al. 2019)

-They go on to say that “... communication in cancer care is often triadic rather than dyadic, involving not just the provider and the patient, but also a family member or friend...”

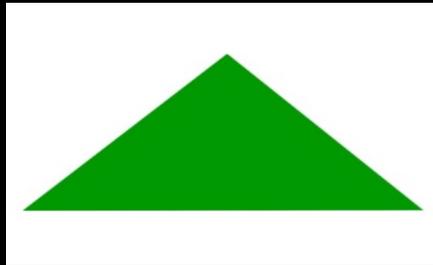


TRIADIC COMMUNICATION MODEL

Greene and Aldeman developed this model and they rightly assert that the addition of a third person increases complexity

-the provider must attend to both and pay attention to both verbal and non-verbal communication needs (Washington et al. 2019)

e.g. You are looking a little tired today, is there anything you would like to talk about?





WHY IS THIS IMPORTANT?



The presence of a caregiver is commonplace in cancer care. In one study a companion was present in 86% of “bad news” discussions”. (Washington et al. 2019)

So we better know how to do it. The writers continue...

“One can more intentionally support caregivers during clinical interactions...inquiring about both persons wellbeing and coping efforts”.

**CARING FOR THE SUPPORTER IS A
FORM OF CARING FOR THE PATIENT**

Often when I meet with patients, they will make a comment like “I can look after me, but I don’t have the energy to look after my partner and family too”.

So, when we look after the partner, or family we are also helping the patient. It can take stress off of the patient to know their loved ones are getting support.





MOST IMPORTANT ASPECTS OF COMMUNICATION



1. Be Attentive– includes taking time, listening, and not being distracted. Make eye contact. Get comfortable with being uncomfortable.
2. Be Genuine vs more distant or “professional” approaches.
3. Be Broadly focused upon patient and caregeivers’ experience.
4. Be Sensitive to unmet information needs e.g. Some caregivers expressed more confusion about patient care.
5. Be Responsive to potential different communication preferences. Some people want the details, other people don’t.

(Washington etal.2019)

**WHILE WE RECOGNIZE CAREGIVERS
AS PARTNERS IN HEALTHCARE....**

It can be very stressful at the same time, and challenges can be in the way....



“THE INVISIBLE PATIENT”

“In some cases, the caregiver has become an “invisible patient” potentially suffering from their own physical and psychological conditions. (bc doctors, 2016)



CAREGIVERS ARE AT RISK FOR DEPRESSION AND ANXIETY

Rivera (2009) states that,

“Depression is a specific emotional reaction to the stress of caregiving. Recent studies have found that 32-50% of caregivers had depressive symptoms at a level suggesting clinical depression.” For those coping with advanced cancer, the percentage can go up to 62%. (Dumont et al. 2006)



MUTUALITY BECOMES AN IMPORTANT CONCEPT



“The diagnosis of cancer has not only a significant impact on the affected patients, but also on their families, and may cause emotional responses of shock, doubt, anxiety and depression.” (Nijboer et al. 1999)

Several studies have shown....that patients and partners did not differ significantly in their stress levels (Nijboer et al. 1998).

So in many ways, when I am assessing one patient and how they are doing, the other may be the same. Thus, if the patient is overwhelmed or anxious, it is quite possible the partner or caregiver is as well. This is the concept of mutuality. In general what we know then, is that cancer is equally if not more stressful for supporters.



Dr. William Breitbart is Chairman of the Jimmie C. Holland Chair in Psychiatric Oncology and is the Attending Psychiatrist, Psychiatry Service, in the Department of Psychiatry & Behavioral Sciences at Memorial Sloan Kettering Cancer Center (MSKCC).

“People with cancer are about 2 to 3 times more at risk of suicide than the general population.”
(2018).

So, if this is a risk for patients, it is important to be mindful of in caregivers and assess as needed.



SUICIDALITY AND FAMILY CAREGIVERS

-There is not a lot of research in this area, but one recent study of 897 cancer caregivers in Korea, found that 17.7 % reported suicidal ideation and 2.8% had attempted suicide in the last year.

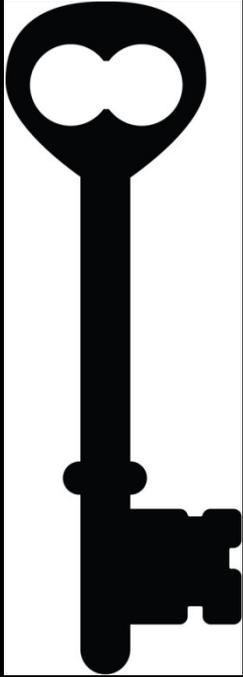
They go on to say, “...we found that the rate of suicidal ideation and suicide attempts in FCs without anxiety and depression was similar to that of the general population...”

Conclusion: “Family caregivers with anxiety or depression were at high risk of suicide. Interventions to enhance social support and to improve perceived QOL may help prevent suicide.”

(Park et al. 2013)

SO, AN IMPORTANT KEY IS....

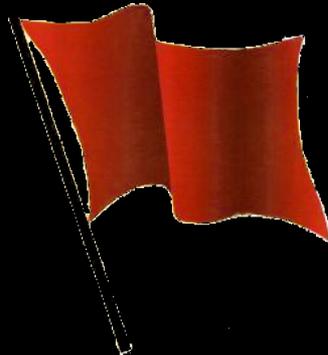
-Assessing for anxiety/depression



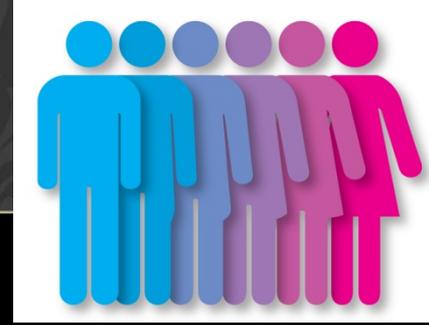
RED FLAG

“ Of all the patient characteristics measure, the level of PATIENT’S DEPENDENCY appeared to be particularly important in the determination of negative caregiver experiences...) (Nijboere et al. 1998)

So, if the patient is highly dependent physically/emotionally on one person that will increase the caregiver’s stress. Perception is the critical factor.



TRADITIONAL ROLES DO NOT ALWAYS BENEFIT WOMEN



-When women are the patient, the partner (e.g. husband) is more likely to get extra support from adult children, other relatives, and friends. It is perceived that they (e.g. husband) needs more help e.g. cooking, cleaning.

Whereas when men are the patient, they receive help primarily from their wives, supporting general gender differences (Kim et al. 2006). There is more of an expectation that it is a women's role to do this.

So, in general, male caregivers get more support from others. Conclusion: Women need to be supported not to take on too much, but also to delegate and do self-care.

STEP 4. PROVIDE INFORMATION AND SUPPORT TO CAREGIVERS

Taking a strengths based perspective and supporting caregivers to make self-care a priority as it is in everyone's best interest (e.g. daily time outs including walks, hobbies, friends, family, enjoying time alone). Caregivers then cope better and the couple relationship may therefore be stronger.

(Northfield and Nebuaer 2010)



PUT THE OXYGEN MASK ON THE CAREGIVER

It is very important that caregivers understand that in looking after themselves, they are also looking after their loved ones, because they will have more physical and emotional resilience for the long run.



TIPS I SOMETIMES TALK ABOUT WITH CAREGIVERS

-As much as possible, try to “live your life in daytime compartments” (William Osler). It is not helpful to live in the past and try not to get too far into the future. Ask yourself, each day, “What do I need to do for myself, to get through today as well as possible?”

Think of this as running a marathon and not a sprint. Pacing is important...

Which means your mantra needs to be “Self-care, self-care, self-care”.

It can be important to take a mental health break or mental health vacation.

If needed then, go out and have some fun and take a break from all of these issues.



**ASSESS HOW MUCH EMOTIONAL
SUPPORT ARE THEY GETTING?**



One research study found that those caregivers who experienced little everyday emotional support perceived caregiving with negativity ...and were more depressed over time. (Nebauer, et. Al. 2010).

Younger caregivers are more likely to experience greater distress...(they) may have other multiple roles to fulfill..." (Kim and spillers, 2009)

Again, any offerings of support are important.

**THE GOOD NEWS FOR YOU...YOU
DON'T HAVE TO ALWAYS DO A LOT**

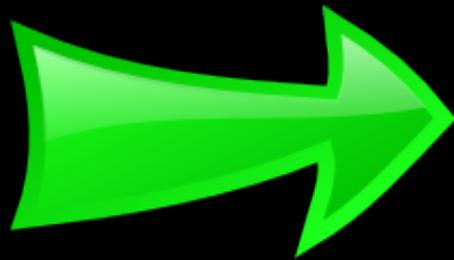


“For instance, studies indicate that caregivers experience less depression when physicians take the time to listen and attend to their needs and opinions.” (doctors of bc, 2016)



**THIS MAY FEEL LIKE ONE MORE
THING YOU HAVE TO DO....**

But here's more good news, you don't have to do it all- because that's what psychosocial oncology is here for. That's our job. To provide emotional and practical support to the patient and their families.



KEEP CALM
AND CALL A
**SOCIAL
WORKER**

GROUPS HELP SUPPORT THE SUPPORTER ALSO

-There are caregiver groups In-Person and Online (e.g. CancerChat Canada)

The great thing about these groups is that the Caregiver is the one getting supported. Almost every other interaction in health care, the patient's needs trump the needs of the caregiver.

In a group or in individual support, they are the focus. In our Mindfulness class at CCMB, it is open to family members as well.



COLLABORATIVE CARE

- Means all disciplines have a slice of the pie
- Psychosocial Oncology clinicians can help provide the support and resources needed individually, for the couple, family, and group wise.
You don't have to do it all.



WHAT HELPS PEOPLE COPE WELL?



Prior QOL is a protective factor in coping with illness. “Good relationships with patients, marital satisfaction, contact with friends, family hardiness, and social support contributed to a positive caregiver QOL”. (Kintungrote, 2006)

Unfortunately, the opposite can be true as in general, close families, get closer through the cancer experience and distant families become more distant as cancer can just become another stress factor in people’s lives.

PTG

While research in caregivers has primarily focused upon caregiver burden, recent research on Post-traumatic growth (PTG) shows us that PTG can happen in coping with adversity or challenges like cancer.

PTG is defined as “...a subjective experience of positive psychological change...as a result of the struggle with highly challenging life circumstances (Zwahlen et al. 2010)



**EVEN IN FAMILIES WITH ADVANCED
CANCER....**

Caregivers valued the opportunity to experience greater closeness, direct communication, physical contact, laughter effective problem solving and time together. PTG can happen.



IT ALSO HELPS TO LEARN HOW TO RIDE THE WAVES

“The caregiver’s experience of coping with ongoing challenges could be likened to the experience of “riding waves”. If the caregiver fights the waves or swims against it, he or she can be pulled under. But, if the caregiver moves with the ongoing challenges of the changing, relentless waves, buoyance and predictability in the ride can be found. (Northfield and Nebauer, 2009).



WHAT HELPS RIDE THE WAVES?”

The authors continue, “Communicating honestly and openly with friends and family, maintaining a daily focus on life, refusing to blame anyone for the cancer...and focusing upon the positives were some of the coping skills employed”.

Overall, religion and spirituality would also indicate a positive outcome for caregivers so long as self-care is part of that understanding





SO, A QUICK REVIEW- 4 EASY STEPS



4 steps to support caregivers: “ Think IIMP!”

1. IDENTIFY CAREGIVERS
2. INVOLVE CAREGIVERS IN PATIENT CARE
3. MONITOR THE HEALTH OF CAREGIVERS
4. PROVIDE INFORMATION & SUPPORT TO THEM

(doctors of bc, Organizing your Practice to Support Family Caregivers- A Tool Kit for Doctors)

SO, IN SUMMARY, THE BOTTOM
LINE IS...

- View Caregivers/Supporters as Partners in Patient care
- Recognize that it can be equally if not more stressful for them
 - Assess for anxiety and depression
 - Take time to check in and be genuine when you do it
 - Think triads
 - Encourage support as needed.



THANK-YOU

