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**The Role of The Cancer Care Coordinator**  
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**Disclosure Statement**

I have no actual or potential commercial or financial conflict of interest in relation to this presentation.


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**Why Provide Cancer Care Navigation?**

1971 – National Cancer Act - President Nixon declared “war on cancer”  
 1.6 billion allocated for cancer research

1989 - ACS issued a “Report to the Nation on Cancer In the Poor”  
 Identified crucial issues and barriers affecting our poor population

1990 –Dr. Harold Freeman at Harlem Hospital, New York City  
 Based on the ACS findings Dr. Freeman founded the first Patient Navigation program  
 Recruited lay people from the community, provided training

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**Harlem Breast Cancer Experience**

**Patient population:**

- Breast cancer, 94 % black, low economic status, ½ had no insurance, treated at Harlem Hospital
- Low number of patients were diagnosed with stage I disease (6%)
- 5 Year Survival rate of 39%

**5 Years later after the community based navigation:**


- 41 % of patients were diagnosed at an earlier stage 0 and 1
- The 5 year survival was 70 %

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**Harlem Breast Cancer Experience**

The two factors identified for the greatly improved results:


- Free or low cost breast exams and mammograms resulting in earlier stage at diagnosis
- Patient navigation improved time to diagnosis and treatment

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**Evolving Definitions and Roles**

The Oncology Nursing Society (ONS) defines patient navigation as:

“individualized assistance offered to patients, families and caregivers to help overcome health care system barriers and facilitate timely access to quality health and psychological care from pre-diagnosis through all phases of the cancer experience”

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### Allina Health Cancer Care Coordinators

- **Primary goal – Ensure seamless, high quality, well coordinated care delivery**
- Partner closely with patients and families throughout their cancer journey - “meet the patients where they are” physically, emotionally, spiritually, cognitively, culturally
- Identify and help remove barriers to care
- Provide education, support, assistance with navigating the complex medical system
- Referral to support services, SW, Integrative Medicine, Cancer Rehab
- Communication is critical – Patient and caregivers, Cancer Conferences, Primary Care Providers, multidisciplinary team

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### Benefits of Cancer Care Coordination

- Reduces anxiety for the patient and family
- Ensures timeliness with staging work up and consults
- Prevents duplication or inappropriate tests (saves money)
- Facilitates communication across the entire health care system – metro, regional, outstate providers
- Individualized patient experience
- Point person, easily accessible
- Patient education, empowers them to make informed decisions

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### Care Coordination Across the Continuum

- Key time points (touch points) on patients cancer journey – initial diagnosis, completion of one phase of therapy, surgery, disease recurrence or progression, end of life issues
- Some diagnosis require complex coordination initially then patient care is handed off to treating team, CCC still on the team for support
- Foster relationships with the other providers and team members

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### Cancer Care Coordination at Allina Health

- 1989 - Autologous Stem Cell Transplant Coordinator  
Provided education, care coordination and support  
Worked under the direction of the Hematologist/Oncologists  
Collaborated with the inpatient and outpatient Care Teams, RN's, SW, Blood Bank, lab
- 2003 – Lung Cancer Coordinator – Jody Eifert  
“It took time to define and refine the role”  
“The role evolved into providing what the patient needed at key meaningful touchpoints during their journey”

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### ANW Esophageal and Gastric Cancer Program

Began in 2005 with a team of dedicated specialists experienced in Esophageal Cancer

- Esophageal cancer is considered a complex cancer- care is recommended at a high volume institution (improved patient outcomes)
- Several staging tests required, multiple specialists, swallowing & nutritional issues, multimodality therapy, complex surgery with high complication rate
- Gastroenterology, surgery, radiology, pathology, medical and radiation oncology, dietitian, social work, nursing, Cancer Rehab, Integrative Medicine
- CCC - followed patient on their journey “Went through the experience with the patient”
- Helped identify areas of need, what was important to the patient and at what timepoint

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### New Esophageal/Gastric Cancer Patients

- New patient referral ensure: patient aware of diagnosis and referral
- Obtain records and review case with provider
- Contact patient –find out where they want their care
- Arrange for work up – NCCN Guidelines (EGD, CT CAP, PET scan, EUS)
- Arrange consults – Med Onc, Rad Onc, Surgeon
- Meet patient – endoscopy center, oncology office, Imaging center
- Provide education material and resources

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### NCCN Clinical Practice Guidelines in Oncology

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### Cancer Care Coordination - Initial Contact

- Goal is to connect with patient within 24 hours of referral – initial call often involves another family member or caregiver
- Explain CCC role and the multidisciplinary team approach
- Listen to their story
- Acknowledge their feelings – many patients haven't even started to process their diagnosis yet
- Prepare them for the next steps, only provide as much information as they want and are able to process – overview of the process
- Set realistic expectations, provide typical timeline and clear plan
- Provide contact information
- Document plan and inform care team

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### Allina Health Cancer Care Coordinators

- RN's with oncology experience
- Qualities of a CCC:
  - Motivated, confident, excellent communicator, team player, knowledgeable, resourceful, empathetic, autonomous, approachable, self-directed, comfortable with high visibility, compassionate, proactive, good sense of humor, reflective, "unwavering advocate", provides a place for hope, flexible

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### Benefits of the CCC Role

- Rewarding, challenging position
- Patient and care giver relationships
- Autonomy, flexibility, variety – every day is different
- Relationships and support from other CCC's
- Always learning, seen as an "expert"
- Positive feedback from patient, families and care team

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### CCC Challenges

- Time
- Limited resources available to patients – transportation, finances (It's expensive to have a cancer diagnosis)
- Working with multiple specialists offices (different EMR, scheduling)
- Building patients/family relationships and suffering loss
- Compassion fatigue
- Patient compliance
- Access to patients either too late or too early in diagnosis
- Changing landscape of healthcare and organization – Insurance, innovative therapies
- Nursing scope of practice

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### The Team!

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### Cancer Care Coordination Across Allina Health

**Disease Specific Coordinators** - ANW, Mercy, Unity, United Hospitals  
 Breast, Cancer Rehab, Colorectal, Esophageal and Gastric, GI, GYN Oncology, Head and Neck, Hematology, Hepatobiliary, Liver, Lung, Melanoma, Neuro Oncology, Pancreas, Prostate and GU, Sarcoma  
 (Referrals often come after a diagnostic test reveals suspicion or has proven a malignancy)

**Generalists** - Regina Hospital, Hastings; St. Francis Hospital in Shakopee; Buffalo Hospital; Cambridge Medical Center; District One Hospital in Faribault; New Ulm Medical Center; River Falls Area Hospital  
 (Often work closely with the PCP's and oncologists in the Community, sometimes prior to a cancer diagnosis)

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### Allina Cancer Care Coordinators in Action

Coordinators partner with local communities,  
 Schools, cancer organizations and patients & families

- Screening and Prevention Events
- Raising cancer awareness
- Health promotion activities
- Education to specific patient populations
- Classroom visits
- Fund raising activities
- Volunteering – Hope Lodge, ACS

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### Powwow For Hope




**VPCI Cancer Coordinators**  
 Jody Eifert, Laura Herman and Julie Kroll with Amy Edwards at the Powwow for Hope

Several organizations partnered with the American Indian Cancer Foundation in their mission to eliminate **cancer burdens** on native people through improved access, early detection, treatment and support for survivors

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### March is Colon Cancer Awareness Month



Colorectal and GI CCC's  
 Dusty Powers, Jessica Milliard and Jessica Steinke with manager Jessica Quinlan-Woodward in the Giant Colon for the Colon Cancer Awareness Event at the Midtown Global Market

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### New Ulm Medical Center Oncology Team




VPCI New Ulm Oncology Team co-hosting "Tea for Ta Ta's"

CCC Susan Gersch is active in the local classrooms providing information and inspiration to students about nursing careers!

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### Volley For The Pink Fundraiser



CCC Marti Auringer is very active with cancer awareness activities at the St. Francis Cancer Center

Annual events include:

- Community Outreach Day (includes a skin screening event and HPV Prevention Program),
- Spring Connect to Celebrate Cancer Survivors, Relay for Life and Volley for The Pink

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### Relay for Life Faribault



In August 2019 CCC Jared Schmitz provided a presentation on Cancer Care Coordination in conjunction with the Rice County ACS

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### Breast Cancer Fun Night



Breast Cancer Fundraiser hosted by Coon Rapids Fire Department and VPCI Mercy/Unity Kristen Eckman & Alicia Anderson posing with some nice CR Firemen!

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### Breast Cancer Fun Night

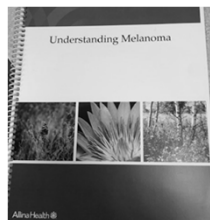


Breast Cancer Coordinators at Mercy/Unity assisted with this fundraiser with proceeds going to the VPCI to benefit patients in need

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### Disease Specific Cancer Education



CCC's assist with Creative Services in the development of patient education materials  
Currently revising/ updating several disease specific patient Ed books:  
Breast Cancer, Colorectal Cancer, Esophageal Cancer, Gastric Cancer, Liver Cancer, pancreas cancer  
Melanoma - 1st Edition  
(These are available in Smart Works on the AKN)

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### Support Groups Coping with Change



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### Allina Health Cancer Support Groups

Many of the support groups are facilitated by a CCC and another facilitator - SW, chaplain, oncology nurse or trained volunteer. Some groups are lead by oncology RN's.

- Brain Tumor Support Group - <https://account.allinahealth.org/events/45>
- Breast Cancer Support Group - Minneapolis: <https://account.allinahealth.org/events/59316>
- Breast Cancer Support Group - St. Paul: <https://account.allinahealth.org/events/18>
- Breast Cancer Support Group - Fridley: <https://account.allinahealth.org/events/30096>
- Breast Cancer Support Group - Edina: <https://account.allinahealth.org/events/7131>
- Breast Cancer Support Group - River Falls: <https://account.allinahealth.org/events/59270>
- Cancer Support and Education Group - Cambridge: <https://account.allinahealth.org/events/57113>
- Cancer Support Group - Faribault: <https://account.allinahealth.org/events/58629>
- Coping with Change - Esophageal, Gastric & Head and Neck Cancer Support Group - <https://account.allinahealth.org/events/59306>

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**Credits**

**The History and Principles of Patient Navigation**  
**Harold P. Freeman, M.D.1 and Rian L. Rodriguez, M.P.H2**  
Harold P. Freeman: hfreeman@mail.nih.gov; Rian L. Rodriguez: rlorodriguez@ralphlaurencenter.org  
Ralph Lauren Center for Cancer Care and Prevention, 1919 Madison Avenue, New York, NY 10035

National Comprehensive Cancer Network - [www.nccn.org](http://www.nccn.org)

American Cancer Society – [www.cancer.org](http://www.cancer.org)


Oncology Nursing Society - (ONS) – [www.ONS.org](http://www.ONS.org)

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**Questions?**

**Thank You!**


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**Whole Person Care**



Dingle Peninsula,  
Ireland  
September 2019

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