PATIENT NAVIGATION PROTOCOL

IN

UNIVERSITY OF NIGERIA TEACHING HOSPITAL

ITUKU/OZALLA, ENUGU

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DEVELOPED BY

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INTRODUCTION

Delivering high quality care to patients presents numerous challenges which include difficulties with care coordination and access. Patient navigation can address these challenges. Patient navigation is a community-based service delivery intervention designed to promote access to timely diagnosis and treatment of cancer and other chronic diseases by eliminating barriers to care (Freeman and Rodriguez, 2011).

Dr Harold P Freeman was the first to develop a patient navigation service to help underserved populations access the health care system. The program's main objective was to remove barriers to cancer care for underserved patients in Harlem. Since then, numerous patient navigation programs have been developed with different approaches and goals for various patient populations, and a substantial body of scientific evidence from many studies on the benefits. Freeman developed patient navigation institute in 2008, to define patient navigation, create standards and also to develop a certification process for people who are trained in the patient navigation program concept. A patient navigation model should be tailored to meet the unique needs of patients, caregivers and navigators and mostly enhance patient's quality of care, and increase both patient and provider satisfaction (Freeman 2006).

Patient navigation is not just for patient navigators only; navigation requires a team approach: administrators to champion the program, supervisors to provide clinical and administrative support, and patient navigators with a defined role within the healthcare team. Patient navigation is a model of care that aims to reduce disease care disparities – differences in the incidence, prevalence, mortality, and burden of disease-related adverse health conditions that exist in a particular community. It addresses the patient's individual barriers to care and links them to existing local and regional resources. When individuals are diagnosed with chronic ailments, they are often overwhelmed. They have feelings that life is going to be dramatically

impacted and changed forever. They are often confused, overwhelmed and unsure. They also sometimes experience denial (this can't be happening!), sorrow (why is this happening to me?), recognition (this has happened, now what?), and acceptance (alright, I am ready to fight this!). Throughout these phases and particularly when entering the acceptance phase, patients need information, support and services. This system of care can provide the life-saving measures needed for patients. Patient navigators also strive to build and strengthen the communication and relationships between patients and health care professionals while addressing psychosocial concerns of patient and family. Another common role of navigators is to close the gaps in the health care system by tracking patient care and ensuring handoffs from one care provider to another.

A fundamental debate revolves around how to define patient navigation and what patient navigation programs should entail, as well as who should provide navigation services. Early efforts relied primarily on non-clinicians. Currently, most navigators are nurses or social workers, tumour registrars, or cancer patient peers who serve as volunteers. Navigation programs are designed to attend to patients' needs in a cultural sensitive manner. Unresolved questions include where patient navigation programs should be deployed and which patients should be prioritized to receive navigation services when resources are limited. Patient navigation systems are often implemented as an attempt to address socioeconomic disparities in care delivery. However, navigation programs often go beyond poor and underserved patient to aid all patients.

WHO IS A PATIENT NAVIGATOR?

A patient navigator is a health professional/social worker that focuses on the patients' needs. The navigator helps guide the patient through the health care system and works to overcome obstacles that are in the way of the patient receiving the care and treatment they require.

HISTORY OF PATIENT NAVIGATION UNIT IN UNTH

The navigation unit UNTH is a unit in oncology centre which is multidisciplinary in nature and effectively caters to the needs of cancer patients. The oncology department of the hospital boasts of seasoned professionals and specialists including surgical oncologists, radiation oncologists, gynaecology oncologists, palliative care unit, oncology nurses, social workers and other staff members. The navigation unit was commissioned in the year 2017 by the then Chairman Medical Advisory Committee (CMAC) Dr Onudugo, with the combined efforts of Dr OkworVitalis and other members of the navigation team and the support of the Director of Oncology, Prof Ezeome. The unit serves as a first point of contact for cancer patients that come to UNTH. Our patient navigation services is designed to ensure that vulnerable and underserved populations receive cancer screening through outreach, timely diagnosis, treatment, improve cancer patients follow-up and overall quality of life. The navigation unit organises periodic support group meeting for the patients to educate them on coping strategies in cancer, follow-up of patients, the role of exercise and nutrition in cancer care, training of survivors for advocacy and patient-patient interaction.

AIMS AND OBJECTIVES

1. Elimination of barriers to health care: Make sure that patients get to follow-up appointments and are aware of and can access needed services.
2. To help patients access adequate care.
3. Ensure timely delivery of services: Assist patients in moving through the health care system as needed in a timely manner.
4. To provide appropriate information for patients to better understand their diagnosis and treatment.
5. To provide psychosocial intervention for patients and caregivers.
6. To link patients to available resources and support services.

SCOPE OF PATIENT NAVIGATION

The scopes of patient navigation include;

1. Letting patients and healthcare providers to know about resources available within and outside the hospital.
2. Wide and efficient use of hospital facilities
3. Promoting patients' care
4. Reaching out to in-patients and out-patients of the hospital to identify their needs
5. Identifying barriers in assess to care
6. Breaking of bad news
7. Organizing and managing patient's schedules and facilitate patient's timeliness to services
8. Managing patient's appointments

9. Outreach (prevention and early detection): Providing health education about cancer from prevention to treatment and ensuring that all patients who have a suspicious finding find resolution through more timely diagnosis and treatment.
10. Diagnosis and treatment: Make sure that patients get to follow-up appointments and help them overcome health care system barriers.
11. Survivorship/rehabilitation (post treatment and quality of life): Patients are followed up through phone calls to ensure they keep to their follow-ups and as well as telling them the necessary diets to be taking. Information on how to maintain positive quality of life are also made available to the patients especially on bi-monthly support group meetings.

ROLES OF A PATIENT NAVIGATOR

1. Coordinate care in the hospital
2. Organizes schedules and manages appointments for patients to ensure they receive services in a timely manner
3. Work across healthcare disciplines to ensure timely appointments, results reporting, and communication on patient care and follow up
4. Direct patients and families to available community resources and supportive services
5. Managing follow up visits and ensuring continuation of care and linkage to community resources.
6. Managing health care records.
7. Informing the patient on financial aspects of care and linking patient to financial resources where possible.

8. Managing health care records
9. Accommodating interpretive language services when needed.
10. Assess clinical, emotional, spiritual, psychosocial, financial, and other patient needs
11. Help develop a treatment plan that is understandable and feasible to the patient
12. Promote community education and increase prevention, awareness and early-detection screening programs
13. Identify barriers or possible barriers to care
14. Educate/reinforce education for patients and families on disease, treatments, side effects, adverse reactions, and reportable signs/symptoms based on multidisciplinary care plan
15. Correcting misconceptions patients have about their illness
16. Acts as mediator between the clinicians and the patients
17. Closes the gap in health care system
18. Training of personnel through organisation of seminars, workshops, conferences and symposia

EXPECTED OUTCOME OF PATIENT NAVIGATION

1. Improved delivery of health care services
2. Reduced patients' and caregiver's unmet needs
3. Improved patient's access to care
4. Reduced co-morbidity
5. Empowered patients with self-management skills
6. Improved understanding of patient's health conditions and their management
7. Improved communication between all care providers

8. Increased sense of partnership with healthcare workers
9. Improved patients/families satisfaction with team communication
10. Improved efficiency of care
11. Improved patients access to quality care
12. Improved health equity for medically underserved population
13. Improved available social support
14. Improved patients' quality of life

IMPLIMENTATION PLAN

- Adequate training of staffs
- Incorporating the various medical personnel into navigation services
- Organizing multidisciplinary meetings for patients with serious cases.
- Organizing support group meeting for patients.
- Understanding of health care facilities and processes.
- Developing evaluation plan with the team for evaluation of the project

RATIONALE

Challenges arise when people contemplate chronic disease screenings. The challenges are multiplied when tests suggest a threatening disease and indicate the need for follow-up investigations. And the challenges expand significantly when such investigations reveal cancer or other life-threatening disease, as people become "patients" in the complex realm of referrals, consultants, examinations, decisions, and often easier-said-than-done treatment regimens (Baquet et al., 2005). Cancer and other chronic disease diagnosis, treatment and survivorship may be confusing, intimidating and overwhelming for an individual, family member and caregiver (Jandorf et al., 2006). Programs should be designed with the

responsibility to assist patients, their families, and to navigate the continuum of health care by developing a navigation program or via a partnership with an organization, community or agency that utilizes patient navigation system.

PATIENT NAVIGATION PROTOCOL

PERSONNEL IN PATIENT NAVIGATION UNIT

1. Frontline health workers: patient navigators, Doctors, nurses.
2. Psychologists, counsellors, social workers, volunteers, survivors and other people

IMPORTANCE OF PATIENT NAVIGATION UNIT

a. To the patient: it is a patient focused based services (explain in reference to patient centred therapy).
b. To the hospital (UNTH): To improve the quality service of the hospital to patients and the community, as well as to promote the image of the hospital against the backdrop that patients don't usually get the best in public hospitals.

STEP BY STEP APPROACH IN RECEIVING PATIENTS IN THE NAVIGATION UNIT

STEP 1: ESTABLISHMENT OF RELATIONSHIP

i. welcoming of patients and offering of seats

ii. Introduction of personnel and services in patient navigation unit to the patient.

iii. Exchange of pleasantries

iv. Offering of water, coffee, tea, etc.

v. Giving of pamphlets to the patients

vi. Making patient feel at home and comfortable.

STEP 2: PATIENTS' REGISTRATION

i. Details of the patients – e.g. Demographics

ii. Brief clinical history of the patients (demonstrate clinical listening when a patient is talking)

iii. Paraphrase the patient's history.

iv. Assess the patient through: observation, discussion or questionnaire base on the level of literacy.

Note: if the patients are in group, focus group discussion is used for their assessment

STEP 3: Identification of the patient's barriers

i. Labelling of the barriers e.g. Emotional, Psychological, Social, Financial, Fear, Treatment, Transportation, Spiritual, Cultural, and Language etc.

ii. Pick the most important identified barrier.

iii. Pre-test – to know the knowledge level of patient about his/her illness and the treatment value.

STEP 4: COUNSELING SESSION

N/B – You can't finish counselling in a day, it is sectional.

i. Go through the case file, in order to have a comprehensive knowledge about the patient.

ii. Identify the psychological intervention suitable for the patient e.g. Cognitive Behavioural Therapy (CBT), Rational Emotive Behavioural Therapy (REBT), Reality Therapy and many more.

iii. Start the counselling with the therapy best suitable for the patient's case

The importance of the therapies on cancer patients

1. It helps to make the patients to understand that they should accept the reality of their health status as the failure to do so is the beginning of any psychological problem.
2. It helps the patients to make the right choice in treatment decision taking
3. It encourages patients to be well adjusted to their condition and make the right decision to get over it.
4. The therapist focuses on how present behaviour can help to meet future needs.
5. It helps patients to stay positive in the of their treatment sessions.
6. The therapy help the patient to solve the problem of excessive anxiety (hypochondriasis) concerning their illness
7. It helps to modify patient behaviour as regards to their treatment

STEP 5: Post –test assessment: this is done after the counselling relationship and treatment on the patient.

Note: The post-test assessment enable us to know if the patient yields to the treatment administered on him/her.

STEP 6

Development of creativity techniques package to facilitate treatment sessions, recovery and survivorship of cancer patients.

These creativity techniques help patients to develop shock absorber to the situational changes in their life. Prominent among this creativity technique include PROBLEM REVERSAL. Let's take a look at problem reversal;

PROBLEM REVERSAL

Thompson (1991) describes the world as full of opposites; of course, any attribute, concept or idea is meaningless without its opposite. Therefore, we need to always consider the other side of life to generate stability in case of unexpected happens. Therefore 7 steps are involved:

1. State the problem in reverse, change negative statements into positive
2. Try to define what something is not
3. Figure out what everybody else is not doing
4. Use the "what if" compass
5. Change the direction or location of the perspective
6. Flip-flop results
7. Turn defeat into victory or victory into defect

STEP 7

BUILDING OF EMOTIONAL INTELLIGENCE FOR THE BENEFIT OF BOTH THE PATIENT AND THE PATIENT NAVIGATOR

It is obvious that there will be manifestation of emotions after the diagnosis, during treatment and after treatment.

Cancer patients are bound to manifest the following emotions

1. ANGER- fury, outrage, resentment, wrath, exasperation, indignation, vexation, acrimony, animosity, annoyance, irritability, hostility, and perhaps at the extreme, pathological hatred and violence
2. SADNESS- grief, sorrow, cheerlessness, gloom, melancholy, self-pity, loneliness, dejection, despair, and when pathological, severe depression
3. FEAR- Anxiety, apprehension, nervousness, concern, consternation, misgiving, wariness, qualm, edginess, dread, fright, terror, phobia and panic
4. Love- acceptance, friendliness, trust, kindness, affinity, devotion, adoration, infatuation, agape
5. SUPRISE- Shock, astonishment, amazement, wonder
6. DISGUST- Contempt, disdain, scorn, abhorrence, aversion, distaste, revulsion
7. SHAME- Guilt, embarrassment, chagrin, remorse, humiliation, regret, mortification and contrition

Thus it's important for us to be sensitive and aware of these feelings and build intelligence around it for quick and speedy recovery through treatment sessions.

STEP 8

Patient adjustment to treatment and its side effects

It has been observed that individuals haveabsolutely no control over what happen to them but the concept of adjustment can help to control how to respond to it.

Adjustment is the use of psychological principle or application of methods and techniques derived fromvarious psychological theories and practices to solve the problem of living.

Such problems of life may include; failure, success, pregnancy, sickness, illness, disease, sadness, emptiness, disability, dying, death, sexual deviation and dysfunction, bereavement to mention a few.

Patients are to develop a kind of adaptation syndrome to face the challenges of life. Adaptation is the process whereby an individual respond to changes in his environment by altering his responses to keep his behaviour appropriate to new environmental demands

Adjustment is a pre-requisite for survival and evolution for all species biologically, psychologically, emotionally and health wise.

Hence, patient should be made to understand that they need to adjust concerning their health status to facilitate their recovery.

AREAS WHERE PATIENTS NEED TO ADJUST

The following are some of the adjustment that can facilitate the treatment sessions of patients

1. Personal Adjustment- This is the ability of an individual to adjust to arising personal issues within oneself, it's the ability to harmonize oneself in the place of challenges and respond quickly to personal changes and keep one's behaviour and actions appropriate to suit personal challenges at any given time.
2. Psychological Adjustment- This is the ability of an individual to be psychologically stable and carry out his/her daily activities effectively. It includes the capacity to reset one's mind to any arising challenges. Here patients are asked to restructure and reset their minds positively as they are asked to develop adjustment for anxiety and depression as they are inevitable challenges for their health status.
3. Emotional Adjustment - This is the ability of an individual to be in control of one's feelings, thoughts, decision and actions. Hence, emotional adjustment is necessary as a pre-requisite for fast recovery of patient in the treatment sessions.

4. Health Adjustment - This is adherence to care givers prescription and warnings. Thus patients should endeavour to build adjustment to their health status such as; attending clinic appointment regularly, taking medication appropriately and as when due, keeping and making use of advice from care givers such as the type of food to eat and lot more.
5. Depression adjustment- This is the ability of an individual to adjust to frustrating situations. It's the capacity to be able to combine and eliminate responses to meet new changes in response requirement as the need arises.

STEP 9

Patient follow – Up: Is divided into two sections

N/B: Every navigator must be assigned to a patient.

SECTION A

Follow up during treatment

i. It is the duty of the patient navigator to be involved in the treatment package of the patient (Laboratory test, Medical review, Surgery, etc.)

ii. Monitoring of their treatment which involves calling

iii. Following them for their tests exercise

iv. Monitoring side effects of treatment

v. Periodic support group meeting for the patient to share their cancer care journey experiences

SECTION B

Follow-up after treatment

i. Adherence: compliance to treatment package. Eg monitoring their drugs in-takes.

ii. Calling to meet up with appointment times for medical check-ups and reviews, welfare.

iii. Psychosocial Education

iv. Home visitation

v. Text messaging

vi. Empowering the patients to become self-independent

vii. Financial empowerment (how they can source for money for their treatment package)

viii. Maintenance of good hygiene (personal and environment cleanliness).

ix. Help to follow-up the referral appointment.

x. Patients are invited periodically to share their cancer journey experiences and to receive first-hand information, nutritional need, psychosocial intervention etc.

Note: Patient navigator duty is beyond pointing of direction for patient.

STEP 10

MONITORING AND EVALUATION

i. Getting up to date information about the patient

ii. Checking what works with the patient and what didn't work with the patient.

iii. Asking reflective questions from the patients.

iv. Check if there is any contextual barrier to the treatment regimen (family, neighbours, disharmony in the family and neighbourhood).

v. Mounting of surveillance: surveillance means continuous monitoring of disease occurrence that is a patient navigator should have a contact with the informal caregiver (members of the family) in other to get feedback on how the patient is doing.

Steps in Outreach

- Identify the target (local government, secondary school, church etc.)
- Notifying the Head
- Mobilizing the materials and human resources for the outreach
- Going for the outreach
- Collect data from the outreach, treat the data and document the findings
- Give referral to suspected individuals to oncology centre of UNTH

Steps in diagnosis/treatment phase

- Welcome both new and old patients to oncology centre of UNTH
- Help the patients and direct them to where they can do some investigations and other units when they are referred to.
- Help in the collection of the patient's results from pathology unit
- Help in the disclosure of the patient's investigation
- Counselling and educating the patients (psychoeducation)
- Giving the patients basic coping mechanisms
- Liaising the patients with other unit and other hospitals if the need be
- Tracking of patients

- Reminding patients of appointments
- Organizing support group meeting for the patients
- Educating the patients on the benefit of treatment adherence
- Educate patients on the side effects of the treatments
- Educate patients on the roles of exercise and nutrition in cancer care
- Home visit if the need be

Steps in survivorship/rehabilitation (post treatment and quality of life)

- Call to know the wellbeing of the survivors
- Educate survivors on ways to stay free from recurrent cancer
- Home visit if the need be
- Organizing skill acquisition programs for the interested survivors
- Educate the survivors on the roles of both nutrition and exercise in life after cancer treatment
- Help integrate survivors on the available resources in the community
- Educate the survivors on the need for regular check-up visitations
- Advise survivors to become advocates

Steps in screening

- Providing screening request form in the Oncology centre
- Sensitizing people in the community about cancer and the need for screening through advocacy patient or interested person comes to navigation unit and counselling and education about cancer will be offered.
- He/she picks the screening request form and pays a token for the screening, the person ticks the cancer-type he/she wants to screen for.
- The person does not need to open a case file for the screening exercise.

- The navigator will accompanies the person to the screening point
- The navigator ensures that the result of the screening is retrieved and a copy filed in navigation unit.
- If the test is positive, the person is counselled, there comes the need to open a case file for the person and the person will be incorporated into the navigation follow-up team
- If the test is negative, the person is counselled and given other cancer screening guides.