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Care of a patient with acute leukemia based on a Dutch specialized model of oncology nursing

In Holland patients with a hematological illness can be treated in any hospital; however, if they are diagnosed with acute myeloid leukemia (AML) of if they are in need of a stem cell transplantation (SCT) they are transferred to a hospital specializing in hematological intensive care (HIC). There are 14 hospitals where autologic SCT is practiced and 5 hospitals where autological and allogeneic SCT are practiced. Within the University Hospital (Vrije Universiteit) autological and allogenic SCT are performed. The hematology ward has 18 beds 3 of which are isolation rooms with laminar airflow and six are day-care beds. In a year about 20 allogeneic and some 50 autological SCT take place. In this paper the presentation of the various responsibilities of the hemato-oncology nurse with the help of a case study of a patient with AML will be done. The structure of this article is based on: *The Dutch professional profile of an oncology nurse* (1).

The diagnosis of cancer starts the beginning of one of the most profound experiences a person can face. The effect of cancer and its treatment on patients and their families has long been the subject of interest and study by those interested in better understanding of the complexity of the psychosocial aspects of this experience and in improving interventions that enhance functional adaptation (2). When observing the range of responses to a cancer diagnosis and treatment, one sees a clear necessity for individualized assessments and interventions. The process of assessment is dynamic, responding to changes over time in the patient's medical treatment, disease course, and adaptation. Interventions are modified as the patient's needs change, and optimally, the psychosocial care is closely coordinated and integrated with the medical team care (4,5). As for the BMT procedure – the specialized two types of nurse are involved in the care, those are the transplant co-coordinator and the apherese nurse. The nurses working on a hematology ward have usually done a hematology and/or oncology specialist course. They have knowledge and abilities to care for the patients with specific needs. The responsibilities of the nurse with regards to the treatment and care of this patient consists of the following activities: – information and prevention, – planning and execute the care, diagnostic and therapeutic role, co-ordination and organization of the care, evaluation and recording, as well the supporting role (6,7).

CASE STUDY OF A PATIENT WITH LEUKEMIA AML[1]

Tim Visser, 38 years old, married to Karin Hartman, 35 years old. They have a daughter, An, 3 years old. Tim is a primary school teacher and Karin works 3 days a week in a bank. An spent two days in a crèche and one day with Tim's mother. Tim has two older brothers and one younger sister. Tim presents with the following symptoms: – extreme tiredness over the last two months; – complaining of recurrent throat infections, he has seen the general practitioner about this on several occasions; – spontaneous broozing over the last 3 days. The general practitioner ordered full blood cultures and discussed the findings straight away with Mr. Visser. He explained to Mr. and Mrs. Visser that Mr. Visser has a serious blood disease and should be admitted to hospital as soon as possible. They pack a few bits and pieces, take their daughter to Tim's mother and arrive utterly devastated on the hematology ward, where a nurse meets them. The nurse shows Mr. and Mrs. Visser the admission room and starts to explain the procedure: • Medical admission by the senior house officer and taking of blood samples; • Explanation by the hematologist, in the presence of the nurse of the bone marrow; • Punction. The bone marrow punction is done as soon as possible to ascertain which type of leukemia Mr. Visser is suffering from; • Basic observations (T, P, RR, length and weight) and nursing admission according to the eleven functional health patterns by Gordon: Health-Perception – Health-Management Pattern, Nutritional – Metabolic Pattern, Elimination Pattern, Activity – Exercise Pattern, Sleep – Rest Pattern, Cognitive – Perceptual Pattern, Self-Perception – Self-Concept Pattern, Role – Relationship Pattern, Sexuality – Reproductive Pattern, Coping – Stress-Tolerance Pattern, Value –Belief Pattern (3).

In the meantime a bed has been prepared for Mr. Visser and he is introduced to the other patients of his ward. Both Mr. and Mrs. Vissers are shocked to see that most of the patients are bold. The nurse shows Tim and his wife the rest of the ward and explains the daily routines on the ward and visiting times. The nurse keeps a careful eye on Tim's well being, as a day like this is very traumatic and exhausting and she adjusts the admission procedure accordingly, priority is obviously given to the bone marrow punction.

THE RESPONSIBILITIES OF THE NURSE

Oncology nurses are and have been committed to supporting, enhancing and positively influencing the Quality of Life (QOL) of patients during the care for cancer. QOL is a process that changes over time and can be modified by certain nursing care interventions. The continued commitment of oncology nurses combined with the knowledge of patients' perspectives of their QOL will help to assist them in achieving the most positive outcomes physically, psychologically, socially, and spiritually (2,4,5). The nurses who work on a hematology ward have done a hematology and/or oncology specialist course. They have knowledge and abilities to care for the patients with specific needs. Throughout the treatment and care of Mr. Visser, who has been diagnosed with acute myeloid leukemia, the nurse has the following responsibilities.

Information and prevention

The results of the bone marrow punction are known later on that day and the hematologist, the nurse and Mr. and Mrs. Visser have a private discussion. The nurse tries to be present during most discussions as she can explain or add to the hematologist explanation. She also notes down

[1] The names of the patent and his family, wa well some demographic date were changed for the publication reason.

what has been discussed, for reference later on. She notes down also the reaction of Mr. and Mrs. Visser.

During this discussion the following subjects are explained: • The results of the blood test and bone marrow punction: Mr. Visser has an AML. The results of the cytogenetica will be known in a few weeks time, which will be important for Mr. Visser prognosis and whether he needs a Stem Cell Transplantation or not; • The treatment in broad lines. Mr. Visser will be treated with HOVON 42 (Dutch/Belgian Hematology-Oncology Co-operative Group) protocol and he has to give a signed consent because he will be part of a clinical trial; • The percentage of patients achieving a complete remission and what a remission means; • The insertion of a central venous catheter; • Explaining the first chemotherapy and that it will start tomorrow, the expected duration of this admission, the side effects and complications of the course of chemotherapy; • How to cope with side effects and complications of the illness and chemotherapy by means of antibiotics, blood products, selective decontamination of the intestines and possible total parenterale nutrition.

Understandably this information is a lot for Mr. and Mrs. Visser to take in. The nurse will be available to explain everything again and again. Complementary the discussion with the doctor, the nurse will discuss preventive measures and how to cope with: • Chemotherapy; she offers written information specific to Mr. Visser's kind; • Side effects and complications, like nausea and sickness, loss of hair, tiredness, sterility, sexuality; Mrs. Visser is not allowed to get pregnant during treatment and a few months after treatment, mucositis (inflammation of mucoses membrosa), pancytopenic period and what measures are taken to prevent or cope with these; • Selective decontamination of the intestines, which drugs, the way they work and the culture regime; • The variety of blood products and their potential complications like an allergic reaction to platelets for instance; • The importance of personal hygiene and the immediate surroundings; • Mouth care; • Germ-free diet; • Practical things like: no flowers or plants, no visitors.

Usually the chemotherapy starts the day after the BM Punction results but because Mr. and Mrs. Visser would like to have more children, chemotherapy is postponed for a day. So Mr. Visser sperm sample can be frozen and stored. It will make artificial insemination possible at a later date. Mr. Visser has to travel to a different hospital, one with a sperm bank.

Plan and execute care

To plan and execute care there is a need to look at the basic cares Mr. Visser requires. It is important to observe what Mr. Visser can and cannot do. In specific the following areas where he might need help: personal hygiene, nutrition and fluid uptake, elimination, posture and movement. Therefore, nurses draw up a nursing care plan and if there is a problem, a useful tool can be the use of nursing diagnoses of The North American Nursing Diagnoses Association (NANDA, 1999) as a part of the nursing process to execute the interventions, outcome and results (8). The nurse is also responsible for the outcome.

Diagnostic and therapeutic role

On admission of the patient, the length and weight was established to calculate the exact amount of chemotherapy. Pulse, temperature, respiration and blood pressure are also measured as basic guidelines. Should the observations be outside normal limits the appropriate action will be taken. Pulse, temperature and respiration will be measured and recorded twice a day and blood pressure and weight will be measured and recorded weekly. But also: provide adequate intake of diet and fluids, obtain a variety of culture samples and blood test, explain results of these test and samples and discuss with the doctor the appropriate action, offer first aid in case of sepsis or bleed, administer oxygen when need a should arise, administer intravenous chemotherapy, blood products, antibiotics, analgesics, anti-fungal medications, total parental

nutrition, give first aid by heart failure, observe and assist during investigative procedures, dissert subcutaneous oral medication like suspension and other medication, once a day control, aseptic care and change the lines of the CVC.

Co-ordination and organization of care

The nurse co-ordinates the care, treatment and investigations of Mr. Visser. She has a daily consultation with the hematologist with regards to Mr. Visser physical well-being, which investigations are needed and which other disciplines are needed, like dietician, physiotherapist, social worker or psychologist. In case of acute complications like sepsis or bleed the nurse takes action and contacts the hematologist on call according to the nursing protocol. If the need should arise, arrage for the hematologist to attend – this will happen, whether it is evening, night or the weekend.

Evaluation and recording

During each shift the nurse records and hands over her findings about Mr. Visser's physical state. Should the psychosocial and/or physical complication become too complex, a meeting will follow attended by multidisciplines to discuss the best way forward. The disciplines who are likely to be invited are; a psychologist, a physiotherapist, a social worker, a chaplain, doctor on duty and the nursing team of that day. For example, during Mr. Visser's treatment he experienced a lack of energy, became immobile and was difficult to stimulate, while there was no particular physical reason for it. The nurses where at loss for answers and the meeting was to provide the right answers and help Mr. Visser to cope better. A big ward round is held weekly, all hematologist, doctors, senior house officers, one of the research nurses, transplant nurse, senior nurse and the nurse looking after Mr. Visser that day attend. During the ward round past, present and future management is discussed of Mr. Visser's treatment. Everything will be recorded on the co-ordination page in the nursing notes. Prior to discharge, Mr. Visser has a private discussion with the nurse who records the contents of the discussion on the co-ordination page and also starts and records in a personal information and communication booklet *The Bridge* which illness Mr. Visser suffers from, what treatment has been started and how his initial recovery has gone. This booklet remains in the possession of Mr. Visser and could also be used by other disciplines. Mr. Visser encounters an outpatient the nurse in the outpatient clinic, general practitioner, transplant coordinator. It is a true record and they can familiarize themselves and add to it. "The bridge" is used on top of all the other mentioned recordings.

Counseling task

The nurse supports Mr. Visser when the hematologist and his senior house officer remove the bone marrow and insert the CVC. The third day of admission Mr. Visser starts his first dose of chemotherapy. The nurse administers the chemo drugs according to the nursing protocol. The chemotherapy is a frightening experience for Mr. Visser. The nurse needs to be aware of this and offer her support. She offers emotional support not only to Mr. and Mrs. Visser but also to their daughter An, and family and friends, because understanding and empathy are needed after devastating news like the illness of Mr. Visser. He is afraid of the treatment, side effects and complications, the results and whether the treatment will work. Mr. Visser is sad and angry over the loss of his health and social position and what that means for him but also for his wife. He is frightened and unsure about the future. The responsibilities of the nurse are not only supportive but also observant. She will offer suggestions how to cope with this fear, sadness, anger and insecurity by acknowledging them and explaining that they are quite normal at this stage. It is important to give the right information and answer the questions honestly. In order to deal with

the problem, she needs to assess, diagnose it and be aware of its symptoms. For example, to diagnose Mr. Visser's anexiety she can use the nursing diagnosis 'Anxiety' (3) if Mr. Visser really has the symptoms and characteristics of anxiety. After this she can use the right intervention. Also his wife will be involved. Mrs. Visser has taken a sick leave at work; it is because she wants to spend more time with her husband and support him, but also because she wants to look after her daughter. They might need help to sort it out, perhaps with the help of medical social worker, psychologist or chaplain (9,10).

THE TRANSPLANT CO-COORDINATOR

Because Mr. Visser is likely to need an allogeneic SCT, the transplant co-coordinator was approached early on Mr. Visser and his two brothers and one sister. After Mr. Visser has had the procedure explained to him, the transplant co-coordinator sets up an appointment with him. Mr. Visser has been encouraged to ask his brothers and sister, when it is necessary, whether they would donate stem cells. If they agree, the first human lymphocyte antigen (HLA) tissue typecasting will take place to see whether one of them is compatible with Mr. Visser. The transplant co-coordinator organizes the first HLA typecasting and the results will be sent to the hematologist (9,10).

THE RESPONSIBILITIES OF THE TRANSPLANT CO-COORDINATOR

The transplant co-coordinator (TxC) is a specialist nurse who sometimes also works on the ward level or in outpatients. The TxC has the following responsibilities: • Co-ordination, planning of necessary investigations, bone marrow punctures and blood samples of donor and patient who are prepared for an allogeneic or autologic SCT, checking if indeed all these have been done and if the results are available; • Offering information and explanation about the SCT together with the hematologist and attending nurse; • Supervising the nursing care of the patient after SCT; • Liaise with doctors and nurses in outpatients, day ward and ward level with regards to pre- or post SCT; • Writing information leaflets for patients and donors about SCT and stem cell donation; • Translating clinical research protocols into nursing protocols and patient information; • Network facilitator: maintaining national and international contacts and from a nursing view and a regional hematological nursing consultant.

THE APHAERESE NURSE

Should Mr. Visser not require the allogeneic transplant, because he has a good risk AML or because his siblings are not HLA compatible and he has an intermediate risk, after his second course when Mr. Visser is in remission, stem cells will be taken. In UW hospital this is done by means of aphaeresis. Mr. Visser will be given Granocyt – stimulating factor (G-CSF) prior taking CD 34 + stemcells. They will be frozen and used if Mr. Visser needs an autological SCT and has not got a donor with compatibility. This procedure is done by the aphaeresis nurse, who also works on the ward level as part of the hematology ward.

CONCLUSION

Just like most patients with a hematological illness, Mr. Visser has been wrenched from social life. When he is admitted for his treatment of leukemia he and his wife start a long hard road to possible recovery. Two chemotherapy

courses and possibly a third or a SCT are necessary. When he finally finished the treatment and is discharged, he did not quite finish. He has to come to terms with having had the illness. Some of the physical complaints might always remain, like extreme tiredness, taste changes, skin changes, fear of the future and the recurrence of the illness. Maybe it is not possible for the patient to return to what it was before he was ill. In recent years much research has been done in order to cope with these problems. Different after-care projects have been started for patients who have treatment for cancer to improve their quality of life (9,10). But the beginning of aftercare starts when the patient is first admitted and continuing during their stay and is then taken on by outpatient's nurses. Furthermore, the hematologist and the transplant co-coordinator both spend time to ascertain the physical and mental well being of the patient, his family and home situation (9).

Therefore it is important that there is not only good liaison between doctors and nurses in hospital, but nurses also need a good contact on the national and international levels (10). On the national level, Dutch nurses have a working party of SCT nurses: The stem cell transplant nurses working in group (LOVeST), who liaise with the nursing group of European Blood and Marrow Transplant (EBMT). This liaison is important in nursing research to improve the quality of care, for instance research in germ-free diet, how to cope with extreme tiredness or what kind of mouth care are necessary for a patient with hematological illness, or if isolation should be considered. It is clear that caring for a patient with leukemia is quite complex and requires specialized knowledge from all the professional staff who are involved in the treatment and care of that patient.

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SUMMARY

Within the University Hospital Vrije Universiteit autological and allogenic SCT are practiced. The hematology ward has 18 beds 3 of which are isolation rooms with laminar airflow and six day-care beds. In a year about 20 allogeneic and some 50 autological SCT take place. In this paper a presentation of the various responsibilities of the hemato-oncology nurse with the help of a case study of a patient with AML is done. The structure of this article is based on *The Dutch professional profile of an oncology nurse*. The responsibilities of the nurse with regard to the treatment and care of the patient consist of the following activities: – information and prevention, – planning and executing the care, diagnostic and therapeutic role, co-ordination and organization of the care, evaluation and recording, supporting role. Two specialized types of nurses are involved in the care; those are the transplant co-coordinator and the aphaerese nurse.

Pielęgnowanie pacjenta z ostrą białaczką szpikową
na przykładzie specjalistycznego modelu opieki w Holandii

System opieki nad pacjentem hospitalizowanym na oddziale hematoonkologii University Hospital (VU)w Holandii jest przykładem wysoce specjalistycznego modelu pielęgnowania. Pielęgniarka realizuje opiekę nad chorym i jego rodziną w oparciu o przyjęte na szczeblu krajowym założenia, które charakteryzują się całościowym podejściem do problemów chorego i jego rodziny. Opis przypadku pacjenta z ostrą białaczką szpikową (AML) odzwierciedla zintegrowany system działań opiekuńczych, w których lekarze, pielęgniarki oraz inni pracownicy szpitala realizują swoje role w sposób komplementarny, zaś nadrzędnym celem jest zapewnienie jak najlepszej jakości opieki choremu i jego rodzinie. Szczegółowe omówienie dotyczy pielęgnowania, gdyż w tym modelu zajmuje ono centralne miejsce, a jest możliwe z uwagi na specjalistyczne przygotowanie pielęgniarek i realizowany w praktyce interdyscyplinarny charakter profesjonalnych działań.