

THE NURSES GROUP ORAL SESSIONS

NO001

The Journey

A Strategy to Enable Patients and Families to Tell Their Story

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Introduction: One great thing about a journey is the memories we collect along the way. The journey through Haematopoietic Stem Cell Transplant (HSCT) has similar challenges to endure, as well as individual patient experiences depending on their own treatment pathway.

Patients and families are so driven and focused on achieving the end result of recovery and discharge, they may not recognise or recall the smaller battles they have faced and conquered.

Method: We recognised that internationally within Oncology services they had developed a strategy which allows patients and families to remember and tell their story, by acknowledging milestones they have achieved. This resource is not available to the immunocompromised child undergoing HSCT. This has led us to develop our own method of recording, saving and storing the achievements of the children and young people, giving them something tangible to prompt their memory and tell their story. The milestones achieved are acknowledged with a symbolic token to represent the accomplishment, which then forms the contents and story of The Journey.

Results: We found that the journey box also offers positive coping strategies in facilitating the child to reflect and talk about their experience during and after transplant, but also offers so much more. For parents, the journey box is a valuable aid to discussion when their child is more able to understand, for young people, the box can store mementos of their journey through HSCT and for bereaved families, providing a secure home for treasured memories.

Conclusion: Whilst the project is in its infancy, this presentation will discuss the process of developing the venture, the content of the boxes and outcomes and feedback with patients and families.

Disclosure of Interest: None declared.

NO002

Nursing care of children with Thalassemia during the Syrian Crisis

An Italian experience in the Autonomous Region of Kurdistan – Iraq

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Introduction: The normal catchment area in Duhok Governorate (Autonomous Region of Kurdistan) was about 1.3 million people. After August 2014 crisis due to the Islamic State, the population increased up to 2.2 million. The pediatric population (40% of total population) increased proportionally, overloading health facilities/services in the city of Duhok. The Thalassemia Center at present (September 2015), welcomes

1,232 patients: 65 are Syrian refugees, 168 are Internally Displaced People from Mosul Governorate, while some 70 new cases are registered every year. The patients have a different age and are affected mostly by β -Thalassemia Major. Patients require transfusion of red blood cells, iron chelation and support for clinical complications in advanced disease.

Method: The overall objective of this project is to contribute to improving the health of the population of Kurdistan. The specific objective is to increase the capacity of Duhok nurses in delivering quality haematological services through: theoretical and practical workshops, job training, introduction of guidelines for nursing team. The first phase of the project consisted in observing and collecting of data relating to Thalassemia Center. The second phase focused on evaluating and improving the nursing care instruments.

Results: The project began in October 2013 and is still on-going, the project was carried out by 2 nurses and 1 doctor, for 27 weeks. After an observation period, it was necessary to divide the health care activities among different nurses so that each of them could perform a single task. The nursing room and the various activities were set up; the patient-flow was reorganized. It was designed and put into practice documentation relating: thalassemia nursing, vital signs, chelation therapy, blood transfusion's check list, platelets transfusion's check list, standard nursing management of the patients. All the documentation has been translated into Kurdish and delivered to the Center. Posters were designed for blood transfusion's and platelets transfusion's check lists, fever, severe transfusion reaction, hands washing, vital signs.

Conclusion: This international cooperation project permitted the nursing training of two Kurdish colleagues, and, through scholarships, they had the possibility to spend 2 months at the Hematology and BMT Units of San Raffaele Hospital in Milan. The nurses learned the importance of the holistic approach to these patients' population. 65 patients with first-degree relative donor with HLA typing of 100% compatibility are now ready to undergo bone marrow transplantation. Many other patients could be sent for HLA typing while BMT Program adopted by the Ministry of Health of the Kurdistan Region of Iraq at the end of 2013 has been able till now to send 26 patients to India and Jordan for BMT.

Disclosure of Interest: None declared.

NO004

Implementing 'Teach-Back' to improve communication with patients attending for Peripheral Blood Stem Cell Collection

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Introduction: Patients receiving pre-collection counselling for Autologous Peripheral Blood Stem Cell (PBSC) collection have a great deal of information to retain. They are not only learning about PBSC collection but simultaneously considering the risks and benefits of PBSC Transplant. Despite verbal and written information, we found that some patients would not remember what to expect during the period of PBSC

mobilisation and collection, leading to frustration, dissatisfaction and logistical challenges. We considered that the 'Teach-Back' method might improve patients' understanding. 'Teach-Back' is a health literacy technique to confirm that the practitioner has explained key points in a way that the patient understands. It involves asking patients to demonstrate understanding using their own words. For example: "I want to be sure I explained everything clearly. Can you please explain it back to me so I can be sure I did?" This shifts responsibility to the practitioner to communicate effectively, rather than on the patient to understand. Our aim was that by July 2015, $\geq 90\%$ of patients attending for PBSC collection reported that they knew what to expect.

Method: An improvement project team was formed to implement Teach-Back as part of autologous PBSC pre-collection counselling, consisting of 2 apheresis nurses overseen by the Charge Nurse. Historical observation of patients led the team to concentrate on two specific points which PBSC patients often seemed unable to retain: (1) Bone pain caused by G-CSF injections and (2) logistical expectations for the week ahead. A staff education session on health literacy and Teach-Back was arranged and as a result the 'Model for Improvement' methodology was employed, and tests of change were carried out using 'Plan, Do, Study, Act' cycles. Specific Teach-Back questions were developed, and ongoing practice improved Teach-Back styles. An improvement clinic with Health Improvement Scotland, resulted in the development of a tool to determine whether Teach-Back was an improvement on our previous counselling approach, i.e. did the patients remember more of what was taught when they came back for PBSC collection. When the team were confident in the success of this process, Teach-Back training was rolled out to the full Apheresis Team.

Month	Patients attending for pre collection assessment	Opportunities taken to use Teach back	Successful outcomes where Teach back was used
May	9	5/55%	5/100%
June	8	8/100%	6/75%
July	6	4/67%	4/100%
August	12	12/100%	10/83%
September	12	11/92%	11/100%
Total	47	40/85%	36/90%

Results: Overall 90% of patients who were counselled using Teach-Back reported that they understood what to expect in relation to G-CSF bone pain and logistical considerations when attending for stem cell collection.

Conclusion: In our environment Teach-Back has been an effective communication technique, improving patients' understanding of key aspects of PBSC collection.

Disclosure of Interest: None declared.

NO005

Holistic Assessment of Patients' Concerns Prior to Autologous High Dose Melphalan (HDM) Haematopoietic Stem Cell Transplant (HSCT) for Plasma Cell Disorders (PCD).

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Introduction: Patients undergoing Autologous HSCT experience a range of physical and psychosocial concerns. The objective of this study is to identify the range of concerns expressed by patients prior to HDM Autograft in order to

- discuss and address individuals' concerns.
- use the evidence to develop and advance services and improve patient experience.

Method: Data were obtained using the electronic Holistic Needs Assessment (eHNA). eHNA is a self-report tool to identify distress levels (0 = no distress, 10 = maximum distress) and concerns in physical, practical, emotional, family and spiritual domains at various time points. The tool was administered to PCD patients in the pre-transplant consent clinic by Clinical Nurse Specialists 1-2 weeks prior to admission for HDM Autograft. Data were collected over a 12 month period.

Results: 46 of 52 individuals offered eHNA completed the assessment (21 F, 25M). Average age of participants was 59.7y (range 33-72y), most common PCD diagnosis was Multiple Myeloma (43/46) and 3 patients were undergoing second Autograft. Lack of time was given most often as the reason for declining assessment.

Total number of concerns was 290 (mean 6.3 per person) with the physical domain incorporating the most commonly reported issues. However, examining the five most frequently reported concerns only three were physical (tingling in hands & feet; fatigue and pain); one was a practical issue (transport) and the remainder was emotional (worry, fear and anxiety). Female patients reported more concerns than men (7.6 vs 5.2) and in particular had 1/3 more emotional concerns than their male counterparts.

Of note, patients younger than 60y ($n=23$) expressed more overall concerns than those over 60y ($n=23$) with those < 60 reporting 70% of the total concerns.

Distress was relatively low (median = 3) (range 0-9). Reasons given for distress included uncertainty of transplant outcome, stress of potential admission delays and side effects/adverse effects of the procedure.

Conclusion: This work highlights that despite patients receiving prior therapy and being assigned a key worker, there were many unmet needs. The breadth of reported symptoms across multiple domains demonstrates the need for a holistic assessment that encompasses every aspect of the patient's health and social well-being.

We plan to respond to these results and in particular address the issues of neuropathy and transport through improved patient information, timely allied health professional input and fully assess pain and optimise analgesia at every opportunity. Implementing early referral to counselling services prior to transplant may reduce the overall emotional burden in this patient group. The unmet needs of the < 60 group are especially marked and it is this population that requires particular focus to uncover their concerns and allocate resources.

Disclosure of Interest: None declared.

NO006

Validation of the German Brief Illness Perception Questionnaire among Long-Term Survivors after Hematopoietic Stem Cell Transplantation - A sub-study of the PROVIVO Study

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Introduction: Long-term survivors after Hematopoietic Stem Cell Transplantation (HSCT) remain at a life-long increased risk for developing physical and psychological late effects. However, there is little knowledge about the HSCT patients' perspective on late effects. The German Brief Illness Perception Questionnaire (BIPQ) has been proven to be a useful tool to examine patient's perceptions of specific illnesses. The questionnaire is based on the Common Sense Model (CSM), which is a self-regulation model of illness representation and coping procedures. So far, the German BIPQ has not been validated in HSCT-survivors. This study aimed to describe the questionnaires' responses and to validate the German BIPQ

according to the *American Educational Research Association (AERA)-Standards*.

Method: Our study applied data from the cross-sectional, mixed-method PROVIVO study including 376 survivors from two Swiss HSCT-centers. The BIPQ consists of eight interval scaled items (range 0-10) and one open question. In a first step, we analyzed the sample characteristics and examined each BIPQ-item descriptively. Secondly, we tested three validity types following the *AERA-Standards*: (1) *content validity indices* (CVIs) were assessed based on an expert survey ($n=9$). (2) A confirmatory factor analysis (CFA) explored the *internal structure*, and (3) correlations tested the validity in *relation to other variables* including the Hospital Anxiety and Depression Scale (HADS), number and burden of late effects and clinical variables.

Results: In total 319 HSCT-survivors answered the BIPQ: suffering from long-lasting late effects turned out to be the most threatening prospect for them (median = 8). The expert-survey revealed an overall acceptable CVI (.82). The items *personal control*, *treatment control* and *causal representation* indicated low CVIs (.78). Based on the two domains of the CSM, the CFA showed that the hypothesized two factor model had a good fit the latent constructs (χ^2 (df) = 956.321, $P=.00$). The HADS-scores correlated strongly with the item *emotional representation* ($r=.648$; $r=.656$).

Conclusion: The validation of the German BIPQ demonstrated generally good validity evidence and therefore shows promise to be a sound instrument to gain deeper insights in patients' perception of late effects after HSCT. However, three items revealed potential problems. Improvements and adaptations in translation are therefore required. Following these revisions, validity evidence should be re-examined through an in-depth patient-survey.

Disclosure of Interest: None declared.

NO007

A photo diary of caregivers everyday life

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Introduction: An increasing amount of responsibility is placed upon caregivers during their spouse's treatment. It is often the caregiver who takes contact to the outpatient unit. This developing study explores how nurses can strengthen the resources in caregivers, so they are able to help their sick spouse in their own home, and to find out if we are doing it sufficient.

Method: A qualitative design with photo diary was selected, and caregivers ($n=4$) was recruited from the Department of Haematology Copenhagen University Hospital, during the spouses control visit at the outpatient unit. The interviews took place at the outpatient unit and lasted between 40-90 minutes. Caregivers were asked to take photos representing their daily life in the role of caregiver.

Results: The photos were classified in five themes; sleeping, feeling warm, medicine, waiting time and nutrition.

All informants had photos of their bed or their couch. They expressed that their sick spouse was tired most of the day. One caregiver felt guilt when it was time to vacuum, and was irritated when they had visitors and he was lay there.

Two informants had photos of their fireplace. They expressed that their sick spouse often was sensitive to cold and they had to light the fireplace, so they could get warm. At times the caregiver had to go outside, because they could not stand the heat.

Medicine was an issue for all the interviewed caregivers. They took photos of all the drugs their sick spouse received. For one of the caregivers the frustration above drug schedule felt a lot, she often had to remind her sick spouse to take the drugs at certain times. Another had bad conscience if she wanted to go out with friends, because she wasn't there to remind her spouse about medicine times.

Waiting time was expressed as a concern by the caregivers, saying that their sick spouse were spending a lot of time waiting in the outpatient unit. After an entire day at the outpatient unit, the spouse were tired and often went straight to bed without supper.

Nutrition was a topic all caregivers mentioned, one took a photo of their refrigerator. The appetite varies during the treatment, one caregiver mentioned that she felt guilty when she was eating. Another caregiver mentioned upon making dinner after the spouse request, the spouse then lost her appetite.

Conclusion: The four interview with caregivers shared a lot of common factors. All talked about themselves in the first part of the interview. The five themes above were the most important for the four caregivers. These five themes give insight into the relevant topics to talk about with future caregivers. Many new treatments are based on outpatient control visit. The caregivers were asked about their opinion about a café for caregivers, where they could meet with other caregivers both in the inpatient and outpatient unit. The caregivers thought it was a good idea, especially in the beginning of the treatment.

Disclosure of Interest: None declared.

NO008

Introducing a co-creative participatory process with patient research partners when developing an internet intervention

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Introduction: Few eHealth interventions have been developed and tested in randomised controlled trials to suit the needs of young cancer patients. One area of great importance for this group is reproductive and sexual health with approximately 50% of patients reporting concerns following cancer treatment. In an effort to develop a psycho-educational program that successfully can alleviate fertility distress and sexual problems we involved patients as research partners, which is rarely done in this research area. The aim is to describe the development of a web-based intervention using a co-creative participatory process including patient research partners.

Method: The development process was based on the holistic framework of developing eHealth by van Gemert-Pijnen *et al.*, 2011. Twelve patient research partners, including 10 former patients and two significant others, were recruited. The research group carried out the development process in collaboration with the patient research partners, which formed the co-creative participatory process. We will describe the impact the patient research partners had on the design of the web-based psycho-educational intervention Fex-Can and the design of the randomised controlled trial.

Results: The input from the patient research partners influenced the design of the Fex-Can intervention by contributing to make information on the website meaningful, relevant and understandable, questioning norms, and creating a professional and persuasive design. The patient research partners influenced the design of the randomised controlled trial by suggesting new measurements and changes in follow-up time, and by questioning the implementation plan.

Conclusion: The co-creative participatory process with patient research partners contributed substantially to the development of the web-based intervention. It has optimized the potential to achieve an effective web-based intervention that

will improve the lives for young adults following cancer treatment.

Disclosure of Interest: None declared.

NO009

Cellular immunotherapy: a Digital Story of HOPE

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Introduction: Narrative medicine is a medical approach that recognises the value of people's narratives in clinical practice, research and education. Narrative medicine aims not only to validate the experience of the patient, but also to encourage creativity and self-reflection in the physician and researcher. It explores the interface between narrative and health care through lectures, readings and performances.

Rupert Suply, a young adult diagnosed with Ewing Sarcoma in 2008, was treated with high dose chemotherapy and autologous hematopoietic stem cell transplantation. He relapsed in 2011 and was included in a study with dendritic cell vaccination to prolong his second remission period. This new therapy slowed down the aggressive tumor growth which gave him real quality time. Being a professional football player and an upcoming DJ before he got ill he decided to combine sports and music to cope with the physical and social isolation he experienced while being continuously treated. He had a drive where you and me can only dream of! Each time the cancer relapsed he fought back with body and mind, was able to stabilise the cancer and went on chasing his dreams. Now it is 2015... His disease is progressive... His girlfriend is pregnant...

Because he is convinced that immunotherapy gave him many extra quality years and he believes in its future possibilities he feels that his story of HOPE is his way of contributing to clinical practice and research.

Method: In a documentary short film, directed by Hedwige Daenens/DigitalStories and produced by Rupert Suply/Suply Hope For Cancer Immunotherapy Foundation, we use narrative medicine to describe our procedure of cell therapy in cancer types where relapse remains a major problem and has an important impact on survival. Rupert tells us his moving story and guides the audience through the different steps in making a cancer vaccine.

Results: Leukapheresis, dendritic cell (DC) generation, antigen loading of DCs by electroporation of Wilms' tumour 1-encoding mRNA, cryopreservation, timing of first vaccination, thawing of the vaccine and immunisation schedule are described by using documentary methods in a hospital and research setting. Each procedure is explained in detail by a qualified member of staff understandable for a general audience. This film shows a series of various interactive scenes at different departments, mostly restricted areas, during Rupert's path creating his personal cancer vaccine.

Conclusion: In the diagnostic process narratives are the form in which a patient experiences disease. They promote understanding between clinician, researcher and patient. In the therapeutic process, narratives encourage a total approach and suggest additional therapeutic options. In the education of patients and health professionals, narratives are grounded in experience, and encourage reflection. In research, narratives help to generate new hypotheses.

Disclosure of Interest: None declared.

NO010

Children's and adolescents' experience of donating bone marrow/stem cells to surviving siblings

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Introduction: Family and sibling relationships are affected in both positive and negative ways when a child in the family is afflicted with a severe illness during a long period of time. The situation that arises when a sibling need to donate bone marrow/stem cells is often of an ethically problematic nature, there are no answers. For example, can a sibling who already has donated bone marrow/stem cells once say NO if the need arises again? How to preserve your child's ability to co-determination through the entire donation process? Because their parents have dual loyalty in these cases it's probably the healthcare givers responsibility to protect children in these situations. There are few national studies conducted in Sweden on how minor siblings who were bone marrow /stem cell donors think and feel about their experience. The aim of this study was to describe children's and adolescents' experiences of donating stem cells to a sick sibling in Sweden.

Method: A descriptive interview study with an inductive approach was performed using qualitative content analysis. The six participants were of both sexes and between 11-21 years. They were recruited from three different children's transplant centers, had donated stem cells before the age of 17 and all had surviving siblings.

Results: The theme *proud heroes without a choice* summarize the results. The category *proud but anxious to be a donor* describes a desire and a joy to help, they feel as proud individuals, surroundings call them heroes, which means that they do not have much of a choice. They also concern how they would endure the procedures and a concern of not being good enough as a donor. They were very anxious all the time for their sick sibling. The category *heroes without real choices in need of support* highlights the strong family ties that do not give them a choice situation for the donation, but a need of support from their friends, relatives and healthcare. They pointed out the need of receiving information but also all of it's weaknesses. The criticism was that the information was too difficult, misdirected and out of focus. In addition, they had wished for more and at an earlier stage. Discussion: What happens to those donors whose siblings die or experiences severe negative consequences of donation? What happened to the hero and how does it feel then? How long last consent to donation – what if there is a need of collecting more stem cells? The psychological risk are something to take into consideration.

Conclusion: These donors were happy to contribute to the sibling's recovery. They were proud and gained a positive view of life from this experience. However the questions remain who will consider the psychological risks of these children and adolescents and if it is right to expose young siblings to this risk.

Disclosure of Interest: None declared.

NO011

Hope for the best yet prepare for the worst: a systematic review of advance care planning prior to haematopoietic stem cell transplantation

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Introduction: Research exploring advance care planning (ACP) has largely focused on people with progressive incurable illness and the elderly. Less is known about the

effect of ACP for people with potentially curable disease that requires high-risk treatment. The aim of this review was to identify the current scientific evidence exploring the prevalence and effect of ACP prior to stem cell transplantation (SCT) for the patient and their carer.

Method: A systematic review of the literature was performed independently by two reviewers across: PubMed; CINAHL; PsycINFO; and the Cochrane Library with inclusion criteria: 1) primary research; 2) English language 3) no restriction on date; 4) no restrictions on methodology; 5) >50% sample had haematological malignancy; 6) participants treated with allogeneic or autologous SCT; and 7) reported on ACP prevalence or associated outcomes. Keywords, synonyms and Medical Subject Headings were used for: stem cell transplant AND advance care planning.

Results: The search returned 84 studies of which 5 met inclusion criteria. Critical appraisal was performed using the Newcastle Ottawa Scale. Most studies were prospective ($n=4$), utilised a quantitative methodology ($n=4$) and had small sample sizes. All of the studies were observational in nature ($n=5$) and three explored the patient and carer perspective. Collectively, it was reported that approximately 50% of patients had a 'living will'/advance directive prior to SCT and these people were generally older than those who did not. A greater percentage of patients had nominated health care proxies; approximately 70%. Engaging in ACP was not reported to be associated with any increase in distress, anxiety, loss of confidence in the medical team (for the patient or carer) or risk of death (for the patient). Two studies reported patients were more likely to discuss their wishes for future end-of-life care with family (63-80%) than the medical team (15-16%). Another study reported that of patients who had engaged in ACP, only half of these patients had the relevant documentation held in their medical record. This suggests disconnect exists between patients' attitudes, behaviours and communication around ACP. Results indicate there was no harm associated with ACP, however, no overt benefit was demonstrated either.

Conclusion: The findings of this review indicate that engaging in ACP prior to SCT is not a routine and well established practice. When performed, ACP was not associated with any adverse outcomes for patients or their carer. As the body of literature on this topic is limited, large observational studies and interventional studies are needed to understand the prevalence of ACP in the SCT population and its effect on patients and their carer. This knowledge will have potential implications for other populations undergoing potentially curable high-risk therapies.

Disclosure of Interest: None declared.

NO012

Patient experience of an autologous bone marrow transplant within an outpatient setting

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Introduction: In 2005 a London hospital opened a unit to provide inpatient haematology care within outpatients. As well as complex chemotherapy regimens, the centre offers autologous and allogeneic transplants. Patients attend daily for care and assessment and are discharged to a hotel nearby overnight. Patients are admitted once unwell. Despite the growth of the service and development of similar units across the UK, there has been little research on patient experience.

Method: 8 patients were recruited, each receiving an autologous transplant for Lymphoma or Myeloma. The researcher interviewed each patient 2-3 times during the process; at the start of conditioning, once admitted to the inpatient ward, and once they are ready to be discharged home. The interviews were semi-

structured; permitting the patients to discuss aspects of the experience that mattered to them.

Results: Previous negative experience of wards increased the anxiety about the transplant when discussed during interview one. On completion of the transplant, the patients complemented the service because of the high level of care they received.

Those who had a relative stay in the hotel found the need for company increased as they felt more unwell. Some unaccompanied patients preferred to be alone but for some it was daunting, and made them increasingly anxious as their toxicities progressed.

Accompanied patients did not discuss the impact the transplant had on partners. Patients staying on their own as spouses worked or had to care for children often described feelings of guilt as their partner took the workload of two people.

Patients enjoyed socialising with fellow patients in the hotel or on the unit but a minority preferred solitude. Some enjoyed the opportunity to go to the cinema, for dinner or to sightsee. Patients recognised when they required inpatient care, with toxicities including fatigue, nausea and diarrhea. Occasionally the staff had to tell patients that they had to be admitted as the patient wished to remain in the hotel, despite being unwell.

The admission process was described as good, as patients were transferred straight to the ward. One patient required A&E admission but described a good experience.

Each patient discussed the appropriateness of their care setting mirroring how they felt. When they were well, they were glad that they were an outpatient but grateful to be an inpatient once sick.

Patients were glad have limited contact from family, friends and other patients whilst unwell. Once their bone marrow function resumed, they were keen to be discharged.

Conclusion: This study offers great insight into the patient experience of an outpatient autologous transplant but also highlights other areas for potential research, including spousal experience of the process.

Disclosure of Interest: None declared.

NO013

Hospital care or home care after allogeneic hematopoietic stem cell transplantation - patients' experiences of care and daily life during the early phase

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Introduction: Treatment at home during the acute post-transplantation phase after allogeneic hematopoietic stem cell transplantation (HSCT) has been an option for patients at the Center for Allogeneic Stem Cells Transplantation, Karolinska University Hospital since 1998. Earlier studies have shown that home care is safe and has medical advantages. The aim of this study was to describe patients' daily life and experience of care at home or in hospital, during the acute post-transplantation phase after (HSCT).

Method: Semi-structured interviews were conducted with 15 patients (six women and nine men) and took place between 29 and 120 days after HSCT. An inductive qualitative content analysis was used to analyze the data.

Results: Nine of 15 patients had experiences from both home care and hospital. The analysis revealed four categories; *To be in a safe place*, *To have a supportive network*, *My way of taking control*, and *My uncertain way back to normal*. The findings showed that patients undergoing a HSCT felt safe regardless of the care setting. To be at home had some positive advantages e.g. freedom, having more physical activity and being with the family. Both emotional and problem-focused strategies were used to handle the uncertain future.

Conclusion: Patients undergoing HSCT have a long recovery period and nurses need to identify individual needs in patients and together identify short- and long- term goals with appropriate support, regardless of the care setting.

Disclosure of Interest: None declared.

NO014

Welcome to Ward 3 at the Great North Children's Hospital – A fun guide to your first two days with us (DVD format patient family information)

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Introduction: Donor stem cell transplant is a significant event for children and families. Ensuring that patients are fully informed and aware of the practical aspects of the inpatient episode was previously primarily undertaken with written information booklets in English and verbal consultation with Consultants and Nurse Specialists. Due to developments in how information is sought and a general consensus that not all of our user group were able to utilize written information in English we felt that using an appropriate visual communication pathway would enhance the preparation of our patient and family group.

Method: The purpose of this work was to develop an alternative communication pathway that would enable us to improve the pre transplant admission information for children young people and their families. The development of the DVD

was focused on the following key criteria; be accessible to families who's first language was not English, to provide appropriate information, be limited to 10-15 minutes in length. The DVD development was initiated using patient and family involvement to ensure that the information was presented in a useful and appropriate visual medium. Two workgroups established the information that should be included within the DVD, workgroup one being input from patients and families and workgroup two being from the multi-disciplinary team. To increase engagement from patients and families we used Graffiti boards, competitions and discussion to obtain information and feedback on the DVD development, at all stages of the process.

Patient and family involvement was key in establishing the outline for development of the DVD. involvement of the multi-disciplinary team worked in conjunction with this input.

Results: Before the DVD was finalised it was reviewed by children, young people, families and staff to ensure that it was appropriate and was a useful tool in sharing the preparation information for the first few days of admission onto the transplant unit. On going assessment of the value of the pre transplant preparation and information formats is undertaken for all patients and families by a discharge questionnaire and this has resulted in positive feedback that appropriate amounts of information are being given.

Conclusion: The DVD has now become an integral part of the information process for patients and families being prepared for donor stem cell transplant within the child and adolescent haematopoietic stem cell transplant unit.

Disclosure of Interest: None declared.