

**THE INDUS
HOSPITAL,
CHILDREN
CANCER UNIT**

**Proposal for Strengthening the Psychosocial
Oncology Department: Child Life Services
and End of Life Care**

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OVERVIEW – PSYCHOSOCIAL ONCOLOGY DEPARTMENT

The Children Cancer Hospital (CCH) was established with modest means in 2001 and is now a 44 bed cancer facility. CCH provides free of cost, specialized and advanced pediatric cancer care. Today, CCH is poised to undergo a metamorphosis from a cancer unit to a center of excellence for treatment and research of childhood cancer in Pakistan. At CCH, we believe that “no child should die in the dawn of life”. This year, we hope to focus more on capacity building, improving patient care and functioning in a paperless environment.

The psychosocial oncology department at CCH was initiated in January 2013 and plays a key role in improving the psychological, physical and spiritual quality of life for the children and their caregivers at CCH. Primarily, this department caters to supporting children and their caregivers with understanding cancer, its treatment and services, coping with emotions and managing illness and treatment, dealing with behavioral changes to minimize disease impact and managing disruptions in work, school and family life. Our objective is to ensure that psychological assessment and counseling is provided to all the patients and their families in order to make their cancer journey easier (*See Figure 1 – Patient Pathway and Figure 2 – Tiered Intervention Model*).

The Psychosocial Oncology Department offers the following 5 services:

- 1. Psycho-oncology** – This relates to the treatment and management of moderate to severe distress and covers issues such as anxiety, depression, self-harm, suicidal ideation, post-traumatic stress disorder, pain management, sexual problems, psychosis, intellectual disability, amputation related trauma, severe pain related distress and grief counseling pertaining to death and dying. Psychological and neuropsychological assessments are conducted to customize treatment for each patient.
- 2. Child Life Services** – These are generalized and aimed at children who suffer from mild to moderate distress. Here we familiarize children with hospital procedures and reduce anxiety regarding medical procedures, help with pain management and aim to provide a sense of normalcy in the child's life. Children who are prepared for medical procedures experience less fear and anxiety, and will have better long term adjustment to medical challenges. Services include family and patient education and support, pain management and developmentally appropriate activities to alleviate anxiety and promote adjustment.
- 3. Spiritual Services** – We work towards alleviating the spiritual distress of the patients and their families through spiritual guidance and exploration and fostering realistic hope. In this area, we aid the child and the family in their existential crises (i.e. addressing questions such as “why me?”, “why my family?”, “will i go to heaven or hell?” etc.). Providing the patient with the feeling that they still have choice and control in their life decisions.
- 4. Rehabilitation Services** - The rehabilitation needs of children suffering from cancer are addressed in a tailor made program to ensure seamless transition to normal life thus improving quality of life. The therapists incorporate play, art and other educational aids to help children

gain back their independence through working on memory, concentration, attention, speech and language, strength building, feeding and swallowing issues.

5. Complimentary Therapy - Art, music, meditation, guided imagery, aroma, touch and massage therapy are all forms of the alternative complimentary therapy paradigm which aid in physical and psychological distress reduction and pain management. These include such activities such as 'reiki', which has been shown to have immense impact on pain management in children especially those who are near death, would not or cannot talk because of their young age or due to severe pain and/or when morphine does not work. Complimentary therapy builds on principles of emotion, compassion and human touch that are required to heal.

For all of the above, psychotherapists are available for inpatient and outpatient consultation services 5-6 days a week. Our staff comprises of a total of 2 psychologists and 1 counselor who together manage all of the services mentioned above. In the summer (June-August), we run a volunteer program and implement various projects in the psychosocial oncology department which are research oriented or evidence based.

With approximately 58 new patients admitted to CCH each month, the Psychosocial Oncology Department is under-staffed with limited resources to meet the growing needs of the patients and their caregivers and simultaneously strengthen our research and training capacity.

In addition to the work that we already do and in light of the above, we propose to implement a number of strategies that would have the greatest impact on services offered in the Psychosocial Oncology Department at CCH, with the aim to create a positive environment and improve the quality of inpatient care.

PROPOSED INTERVENTIONS




The following strategies and action items are proposed to enhance the services offered specifically in the psycho-oncology, child life services and spiritual services offered at CCH.

Creating a Child Friendly Environment

It is well-established that a patient's environment has a great impact on his/her health and his/her attitude towards treatment. An encouraging, colourful¹ and child friendly environment, builds a positive attitude and removes negative perceptions associated with being in a hospital. Such an environment does not currently exist at CCH. In order to create such an environment at CCH, we propose to procure the following items, which will all come together to improve a child's experience at CCH². (*Details of each are in Appendix A*).

¹ Maggie Redshaw. *The impact of a new hospital environment on children, families and staff* (2002)

² These ideas are based on the needs of CCH and through learning from other hospitals such as St. Judes, Queensland, Alberta Children Hospital, Birmingham Children Hospital, Cambridge University Hospital

ITEM ³	PURPOSE
Bedside Basket	<ul style="list-style-type: none"> - Engage children to distract them from distress, pain and boredom - Will be hung or placed at the side of each bed - Contains colour pencils, colouring books and story books
Chemo Care Kits 	<ul style="list-style-type: none"> - Each child requiring chemotherapy will be given a Chemo Care Kit once - These help with managing side effects from chemotherapy and in providing needed distractions for children and their families - The Kit for side effects includes such items as mints, which help with the bad taste in their mouth; lotion and lip balm to help patients' dry skin/nails; fun cap for hair loss, etc. - Includes activity and comfort items that help the child become familiar with the procedures and provides a positive association with the hospital
Cots (for infants/ toddlers)	<ul style="list-style-type: none"> - More suitable for infants birth to 2 years of age, which is safe, child friendly and occupies less space - Possible to hang mobile toys from them, hence a good source of distraction - To optimize the use of space on beds (since when infants occupy a bed, more than half of the bed space is vacant)
Pain Management using 'Buzzy' 	<ul style="list-style-type: none"> - Decreases the pain of IV insertion in young children, creating distraction and relaxing the child
Toy Trunk/Chest 	<ul style="list-style-type: none"> - A bright, colourful box to hold all the toys in the rooms and daycare

Magic Distraction Kits	<ul style="list-style-type: none"> - To distract the child from the inoculation processes being carried out and provide relief from anxiety and pain - These can be installed in each ward (two in the daycare ward) where inoculation procedures, etc. are carried out - The nurses will be introduced to and familiarized with the kits and their usage beforehand in a session so that they can use the kits efficiently - Nurses will keep a check on the articles in the kit and need for re-filling or replacement
Sanitizers	<ul style="list-style-type: none"> - To get attractive sanitizers around the hospital so that children use them sufficiently. These can be covered in stickers or they can be painted over with bright colours and cartoon characters
Aquariums	<ul style="list-style-type: none"> - Water and fish attract children creating a dynamic and fun environment, in which children can have fun watching colorful fish playing around in the water. Moreover it is extremely relaxing and serves as a distraction.

The following items are also very important to our effort of strengthening the psychosocial environment at CCH. While these are not on our current list of items to be procured through this grant, every effort will be made to procure the following items from toy/donation drives over the course of the year.

Reception	<ul style="list-style-type: none"> - To provide a warm welcome to children when they first enter CCH - Includes balloons; bowl of candy, stickers
Hospital clothes	<ul style="list-style-type: none"> - To foster a more child friendly environment - Children usually balk at regular hospital clothing and prefer ones with cartoon characters or which are colorful
Wall decorations	<ul style="list-style-type: none"> - To keep each ward different and fun through wall mounts, life size stickers and panaflexes decorated according to different themes of children's interest - Aid in distraction and cheering up young children - Easy to clean, remove and re-use

White Board with Stand	<ul style="list-style-type: none"> - Will be placed in every room - Can be used in group counseling sessions and for teaching (by volunteers) - Can be used to write down daily schedules (hours of play time, doctors' visits, food and rest time), to help children regain control over their daily activities
Colorful bed sheets and curtains	<ul style="list-style-type: none"> - Create a colourful, fun and relaxed environment - Bed sheets and curtains with cartoon characters would make the hospital environment less intimidating
Video Games	<ul style="list-style-type: none"> - Help reduce anticipatory symptoms and improve strength and behaviour in cancer patients - For older children (with basic knowledge of PCs) - Non-portable gaming devices are more expensive, but cannot be easily damaged (as compared to portable gaming devices)
	<ul style="list-style-type: none"> - LCD's are already installed in almost all the wards, which would allow Xbox and Play-station to be set up there easily - PC games can be played online and downloaded for free - The computer lab at CCH can be made available for a few hours every day for children to play video games on

Psycho-Diagnostic, Psycho Therapeutic Tools; Workshops & Supervision

Psycho-diagnostic and psycho-therapeutic tools (e.g. the Thematic Apperception Test for young and old children (CAT and TAT)) serve as great assessment and psychotherapeutic tools in helping children express their fears, anger and other repressed emotions. There are also numerous other tests that measure depression, anxiety, stress or trauma and which help therapists in gauging the level of distress throughout the treatment continuum. This not helps in identifying children needing immediate psychotherapeutic intervention but also identifies the types and severity of disorders they may be suffering from. The tests cater to all age groups hence; we want to purchase tests that are age appropriate. The assessment tools also aid the team in helping identify stressors in the child's life which the child may not be able to express otherwise. Numerous books are available that are aimed especially for children who are unable to express their emotions. These are proven to aid in therapy.

These psycho-diagnostic and psycho-therapeutic tools further help in assessing the pre-intervention and post intervention state of child, subsequently telling us whether or not the interventions being implemented are having a positive impact. These tests ensure that the child is diagnosed correctly, therefore getting the right treatment at the right time. Research itself is a great tool to ensure that work being done is evidence based. The child undergoing chemotherapy or suffering from cancer spreading to the central nervous system will need to be monitored for neuropsychological deficits which, when identified at the right time and correctly, will ensure

treatment to help the child overcome problems associated with CNS involvement. Chemotherapy or radiation itself impacts memory and neural functioning which can be identified with the help of these tests and treatment can be tailored to meet the needs of these children.

In order to maintain the best possible practice, continuing education for the therapists on staff is mandatory. This is an integral component of any program, such as ours, that is intent on continuously evolving and producing cutting-edge work. Workshops that we have up participated in thus far include end of life care, trauma management, and child development. These are carried out by trainers from both within and outside Pakistan. We ensure that we are up to par in counseling skills. Supervision is also an important part of practice which ensures accountability and responsibility. We have incorporated a hierarchy of supervision entailing reporting to our immediate senior. We have been trained in the American Psychological Association's ethical guidelines, of which supervision and continuing education is a significant factor.

Staff

To enhance the work of CCH, we hope to expand our team to include 2 more (part-time) Child Life Specialists and 1 End of Life Care Specialist (providing round the clock services). These specialists will work with children on mastering feelings of fear, confusion and unfamiliarity with events and medical experiences through play, education and support. Child life specialists provide opportunities for building independent behaviour and retaining self-esteem. They provide a continuation of regular daily activities to promote normal growth and development. Children who are prepared for medical procedures experience less fear and anxiety, and will have better long term adjustment to medical challenges. End of Life specialists work with both parents and children to alleviate the trauma associated with the end of life and help answer existential questions such as „why me?“, etc. Moreover, End of Life specialists prepare the child and family for the final hours, death anticipatory anxiety and post-death distress.

While it is optimal to ensure that our personnel have specialized training, we will also be training them on multiple aspects of Psychosocial Oncology. This ensures that there is a wide range of skills available that our department can offer.

We also hope to recruit a Coordinator on our team. His/her role will be primarily administrative and will include the following tasks: organizing the volunteers, procurement, managing inventories, and maintenance of items procured, research and training coordination, ensuring record keeping of evaluation forms, and data entry (as and when appropriate). The Coordinator would also facilitate additional fund-raising efforts and initiatives such as a toy drive, etc.

Orientation/Support Groups

As a pilot, the Psychosocial Oncology Department will hold a monthly orientation session followed by support groups to familiarize and provide psychosocial support to the patients and their caregivers. These sessions will have approximately 55 patients and their caregivers. The audience will be introduced to key personnel in the hospital such as oncologists, infection control, psychosocial team, nurses, social workers, etc. who will talk about their involvement with the patient's treatment. This will be followed by a video presentation of the hospital's

premises and services as well as a question and answer session. Tea for all and goody bags for the patients will be handed out, which will further help create a positive and welcoming environment. We will assess the feasibility of this activity after the first month to see if it can be easily conducted on a recurring monthly basis.

Training

We hope to provide opportunities for our staff (especially nurses) to get appropriate training in providing psychosocial support to children with cancer and their parents. Examples of this training are:

- Nurse Technician Course (3 month basic course)
- DPON course (3 months advanced course) – this includes modules on child development theories, person-centered care, comfort position, pain management techniques, caregiver care and compassion fatigue. These trainings will be carried out by the psychosocial oncology staff and will be held in the hospital premises. Tea/lunch will be served
- End of Life Care – This 6-week course will include modules on grief counseling, and end of life care for nurses and caregivers. These training modules will be carried out by the psychosocial oncology staff and will be held in the hospital premises. Tea/lunch will be served.

Funding for these trainings is currently provided by CCH and therefore no additional funding is required for this activity.

EVALUATION PLAN

The impact of all of the above interventions will be measured through various evaluation tools. These include:

- 1) **Evaluation/Satisfaction surveys** – These feedback forms will be regularly compiled from parents, patients (where appropriate) and health care staff.
- 2) **Distress thermometer** (pre and post intervention) – (*See Figure 3*)
- 3) **Wong Baker Faces Pain Scale** – (*See Figure 4*)
- 4) Depression, anxiety and stress **measuring scales** may be used, pre and post intervention to gauge how much so positive impact the interventions have had.
- 5) We will administer **feedback reports** to ensure that this an improvement in the knowledge level of the trainee (such as volunteers, nurses, staff, etc.).
- 6) **Observation notes** - We will encourage our staff to take more detailed observation notes of the patients so that we can better assess and evaluate changes in mental health through the course of treatment and resulting from various interventions. Currently, due to a lack of

human resources, staff have limited amount of time to take detailed observation notes. These reports will be used to improve the quality of care being provided and to assist with supervision of the staff. Supervisors will be able to provide oversight and guidance based on these reports.

- 7) **Electronic Medical Records** – Over the next year or so, we hope to transition towards electronic medical record software that would allow us to more extensively capture the effects of the work we are doing and to ensure that a rich amount of data is collected in a timely manner. However this is dependent on when new software is installed. At present we are using the software provided by the Indus Hospital, which presently restricts the amount of notes that can be taken.

Through these mechanisms, our strategies will be continuously improved to ensure we reach maximum levels of quality.

The work-plan/timeline will be the key way to ensure adherence to the commitments made in this proposal. Activity reports, number of beneficiaries reached and measured patient/caregiver satisfaction levels will be shared on a quarterly basis to keep track of our progress. The psychological assessment tools that we will use pre and post interventions will give us a qualitative and quantitative account of the services we need to offer and help to ensure that these needs are being met. We are cognizant of the fact that since we are relatively new department, we will need to continue to learn and adapt our strategies to ensure we optimize our resources for maximum benefit.

We will also conduct various research studies to keep abreast of our best practices and to ensure that the resources we utilize are done so in the most cost-efficient manner. We will analyze the cost-benefit analysis of the various interventions. For example: we will measure the positive impact of video games or buzzy (used during venipuncture) on children by having a control and experimental group. If there is a positive impact of these, we can raise additional funds to procure more of these for the CCH.

SUSTAINABILITY

In order to ensure sustainability beyond the year that these funds are available, we are working with the hospital senior management to ensure that next year's financial budget include the additional staff from our department. Hence these positions will be funded by the Indus Hospital. We are currently in conversation with senior management about this possibility and are hopefully for a positive response. We have every intention of finding the resources to cover these staff costs since it is an integral part of the patient care program to improve quality of life.

FUTURE PROJECT

We would also like to get an Art Therapist and a Sound Therapist on board (for next year) who can help us create a program utilizing their expertise for the children. The therapists have been identified and we are currently in the process working out the details of such a program (conditional on funding). It has been found that art and sound are two means which children naturally gravitate towards, especially given that a number of children who are admitted to CCH face a language barrier. Art and sound are two mediums which don't require language. They are especially aimed at children who are unable to express their emotions effectively and who repress their emotions for fear of upsetting their families who are already in distress. This creates further distress for the patient who not only has to deal with his illness but also the emotions associated with it, which include fear of losing bodily control, excruciating pain or dying. Art and sound not only serve as great therapeutic but also assessment tools. Funding for this plan will be sought from other sources.

CONCLUSION

This proposal contains a number of strategies to improve the standard of mental health care and services provided in the Psychosocial Oncology Department. These have been compiled based on current needs of the department, health care staff observations, and extensive market research. With the help of volunteers, every effort will be made to initiate drives for toys and donations, to ensure sustainability of our efforts and to utilize additional funds for our proposed interventions.

Figure 1. Patient Pathway

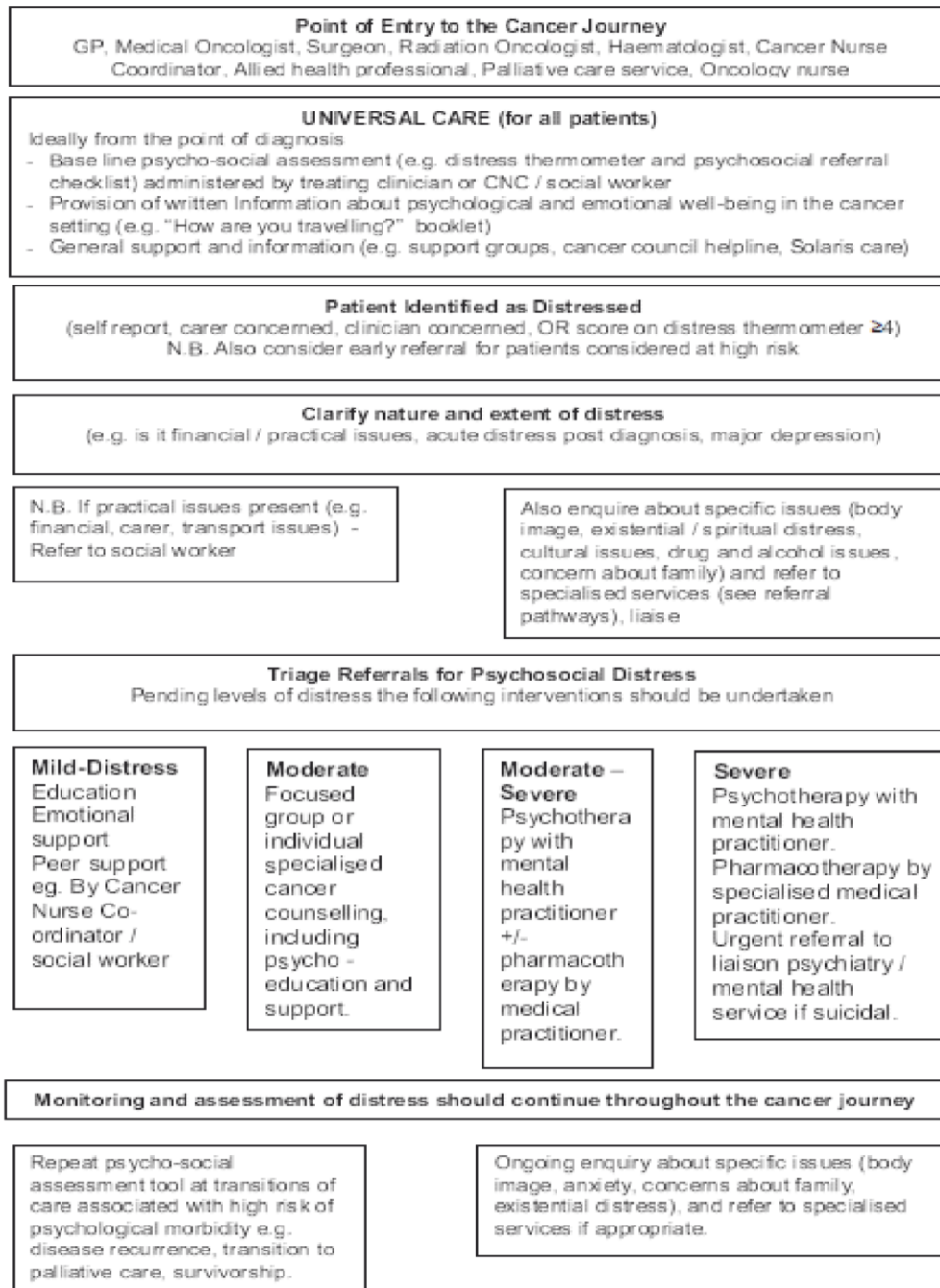


Figure 1 Adapted from:
 (Hutchinson, Suzanne, & Dunn, 2006; and NBCC & NCCI, 2003)

Figure 2. Tiered Intervention Model for Psychosocial Interventions

Adapted from Hutchison, Steginga & Dunn (2006, p. 534).

Level of Distress /Complexity of Need	Methods	Relevant Services	Example of Psychosocial Issue
Minimal-mild	General Information Sharing	Primary Care Team Telephone help-lines Printed & audiovisual productions	Side-effects of medications/treatments. Practical concerns
Mild-moderate	Psychoeducation & emotional support Peer support	Hospital or community based support programs, eg. cancer social worker, clinical nurse co-ordinator, Telephone help-lines	Treatment decision making Problem solving and coping strategies
Moderate	Focused individual, couple, family or group counselling including psychoeducation and support	Cancer specific hospital and / or community based counselling services	Adjustment to cancer, grief Stress management Coping skills
Moderate to severe	Psychotherapy , Couple & Relationship Therapy, or Family therapy with mental health practitioner	Hospital/community based psychotherapy services specialized in the needs of cancer patients and their carers / families.	Mood & anxiety disorders, Trauma, relationship and sexuality problems
Severe	Psychotherapy with mental health practitioner Pharmacotherapy by medical practitioner	Specialist Community and hospital based mental health or psycho-oncology teams; Psychiatric Inpatient facilities	Multiple, complex psychiatric difficulties Risk issues Severe personality and relationship functioning

Figure 3

NCCN®

Distress Thermometer

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10

9

8

7

6

5

4

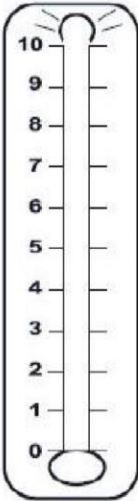
3

2

1

0

No distress



Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems		YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child care		<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing		<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial		<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation		<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school		<input type="checkbox"/>	<input type="checkbox"/>	Constipation
				<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
				<input type="checkbox"/>	<input type="checkbox"/>	Eating
				<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
				<input type="checkbox"/>	<input type="checkbox"/>	Feeling Swollen
				<input type="checkbox"/>	<input type="checkbox"/>	Fevers
				<input type="checkbox"/>	<input type="checkbox"/>	Getting around
				<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
				<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
				<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
				<input type="checkbox"/>	<input type="checkbox"/>	Nausea
				<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
				<input type="checkbox"/>	<input type="checkbox"/>	Pain
				<input type="checkbox"/>	<input type="checkbox"/>	Sexual
				<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
				<input type="checkbox"/>	<input type="checkbox"/>	Sleep
				<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

Other Problems: _____

DIS-A

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Figure 4

