Screening for patient's distress and supportive care needs : is it a way to improve quality of care ?

IBDC, Paris, february 8th 2013

Session 7 : Patient Support

S Dolbeault* , A Brédart* , P Teillac**

* Supportive Care Department

** Direction of Ensemble Hospitalier

Institut Curie, Paris

institutCurie

Context

Interdisciplinary Supportive Care Department of Institut Curie, Paris

- integrates diverse competences : psycho-oncology, palliative care, social work, nutrition, rehabilitation**,** addiction, tumour wounds, oncogeriatrics *(in 2013 : 70 equivalent full time professionals)*

What can we do from the diagnosis period and during treatment phase to give appropriate answer to patient's distress and needs AND to anticipate Supportive Care needs of patients who will be in remission ?

institutCurie

Definition of Supportive Care

MASCC definition (1992)

« Supportive Care in cancer is the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship and end of life care are integral to Supportive Care ».

http://www.mascc.org

- Each step of the treatment and rehabilitation period is included
- Treatment of side-effects and post-treatment sequela, **including screening and an appropriate response to patient' psychological distress and unmet needs**

institutCurie

Aims of Supportive Care

To allow a better clinical management of vulnerable patients defined by a high level of complexity

Continuity of care perspective

but also a better recognition from the medical community of the importance of global and patient's centered managed care

institutCurie

Screening distress and unmet needs : what to do ?

institutCurie

MASCC and IPOS

MASCC Multinational Association for Supportive Care in Cancer

http://www.mascc.org/

French Branch AFSOS Association Francophone pour les Soins Oncologiques de Support
http://www.afsos.org/

IPOS International Psycho-Oncology Society

http://www.ipos-society.org/

French branch SFPO Société Française de Psycho-Oncologie
http://www.sfpo.fr/

institutCurie

Work of the NCCN for the last 12 years

NCCN : National Comprehensive Cancer network

Defining Distress

« An unpleasant experience of a psychological, social and/or spiritual nature which extends on a continuum from normal feelings of vulnerability, sadness and fears to disabling problems such as depression, anxiety social isolation and spiritual crisis »

(NCCN 2001, Guidelines 2010)

2010: Distress is recognized as the 6th vital sign

Special Issue: Screening for Distress, the 6th Vital Sign
June 2011
Volume 20, Issue 6, 569–674
Issue edited by: Barry D. Bultz, Christoffer Johansen

institutCurie

Why is it important to screen distress ?

*** High prevalence :** 30 to 40 % with a number of identified risk factors

(NCCN 2004, Carlson 2004 and 2012, Jacobsen 2007, Mitchell 2011)

Notion of clusters

(Gwede 2008, Fleishman 2004, Miakowski 2004 et 2007)

*** Not screening distress :**

- **Worse quality of life** ***(Zabora 2001, Kornblith 2003, Velikova 2004)***
- **Higher sensitivity to symptoms** ***(Breitbart 1995)***
- **Less satisfaction / care** ***(Brédart 2001 et 2006)***
- **More coping and compliance troubles** ***(Mitchell 2006)***
- **Heavier costs** *(Carlson 2004, Bultz 2005, Strong 2008)*
- Survival ? Many contradictory studies *(Watson 1999, Dalton 2002 et 2009)*

*** Health professionals ability to screen distress is low** :

many barriers to communication

(Newell 1998, Passik 1998, Maguire 1999, Fallowfield 2001, Söllner 2001, Schoefield 2006, Holland 2005, Velikova, Razavi …)

→ ***We have to organise screening procedures and develop simple screening tools to detect patients in distress***

institutCurie

Using « Patient Related Outcomes » in the daily practise

To systematically integrate subjective measures to facilitate screening of patient's problems and need for help

(Velikova, Snyder 2007, Lohr 2009, Mitchell 2011, Carlson 2012)

*** Experiences with quality of life**

(McLahan 2001; Detmar 2002; Velikova 2004, 2007, Rosenblum 2007; Hilarius 2008)

Done by doctors and/or nurses
T*ouch screen* Implementations
using CAT (*Computer Adapted System*)

(Petersen 2006, Smith 2007 et 2009)

*** Experiences with distress**

(Maunsell1 996, Boyes 2006; Jacobsen 2007,Carlson 2010, Bultz 2010)

… Psychological distress as « the 6th vital sign »

(Bultz Carlson 2007, 2010)

*** Experiences with patient's needs**

(Snyder 2007)

institutCurie

How do we screen psychological distress ?

(NCCN, Jacobsen, Mitchell, Coyne)

* **In a majority of studies, 2 step procedure :**
  - A basic and easy to use screening tools (all professionals)
  - A cut-off score above which referral to specific professional is organized (psycho-oncologist, social worker, nutritionist …)

Guidelines NICE, CAPO, Australia, United Kingdom, Germany

(Jacobsen 2007, 2009; Bultz 2011)

- instruments most commonly used : HADS, CES-D, BSI, GHQ … *(Mitchell)*

- **The NCCN *Distress thermometer***

institutCurie

Screening methods being gradually improved…

Many developpments have been done, starting from the *Distress Thermometer* *(Vodermaier 2009)*

- **Addition of a Needs Scale** *(Mac Lachlan 2005)*

eg : Supportive Care Needs Survey (SCNS-SF34) 5 domains : physical, emotional, patient care, sexuality, information needs

(Snyder et al, 2009, validated in french *Brédart, Kop, Dolbeault 2012)*

- **Combination of different tools :**
  - Distress and its impact *(Akizuki 2005)*
  - Distress and affective troubles *(Gil 2005)*
  - Distress and other clinical dimensions (anxiousness, angryness ..) *(Mitchell 2007, 2008, 2012)*

- **Variation of distress cut offs**

institutCurie

Screening for cancer-related distress : what's the impact ?

Screening tools do improve screening by health professionals

(Greenhalgh 2009)

Screening seems to improve communication between clinicians and may enhance psychosocial referrals

(Carlson 2012)

What is the impact of screening on psychological well being ?

(Bidstrup 2011)

Review of 7 RCT of the effect of screening for psychological distress on psychological outcomes :

3 positive, 1 positive only among depressed patients, 3 negative

institutCurie

Why is it important to screen Supportive Care Needs ?

Patient's supportive care needs are diverse, depending on the moment of the cancer journey

Diagnosis

Difficulties : anxiety, fear, anger, depression; access to information, difficult decisions

Needs : Information, psychosocial, access to the benefits/risks of different treatments' options; communication with medical team; shared decision making

(Andersen 2009; Armes 2009; Miller &Massie 2010; O'Connor 2011; Stanton 2006; Sutherland 2009)

Treatment

Difficulties : Toxic side effects, Body change, feminity, fertility, social role

Needs : Physical functionning/daily life, Find support to deal with side effects, Psychosocial

!Harrison 2009; Montazeri, 2008; Rowland &Massie, 2010; Sanson-Fisher 2000)

Follow Up

Difficulties : Losing hospital reassuring effect, fear of recurrence, pain, fatigue, physical and sexual dysfonction, cognitive troubles, psychological distress

Needs : psychosocial, help for daily tasks, cope with pain, fatigue, information about supportive care possibilities, get information about the status «remission »

(McDowell 2010; Armes 2009; Schmid-Buchi 2008; Ganz 2005, Stanton 2005)

… impacting Quality of Life

institutCurie

But … positive change can also occur

Studies among breast cancer women after cancer treatment

After one year, many breast cancer women have a quality of life similar to the general population

Why ? **PTG: post traumatic growth**

(Stanton 2006; Yang 2008; Lelorain 2011)

Some forms of support early during the cancer trajectory has been linked to better adjustment and can predict PTG years later

(Cicero, 2009; Schroevers 2010; Scrignaro, 2011)

institutCurie

Needs at diagnosis versus needs at the follow-up period

Higher unmet needs at the beginning of the cancer journey PREDICTS higher unmet needs later on along the cancer trajectory

(McDowell 2010 ; Griesser 2010 ; Akechi 2010)

institutCurie

Follow Up

Predicting needs

- Anterior unmet needs
- Minor satisfaction / care
- Problems with physical statut, sexual troubles
- Younger age, lower education, lower supportive relations, psychological caracteristics (pessimism, poor self efficacy; intrusive or avoiding thoughts)

(Avis 2004; Mc Dowell 2010; Griesser 2010; Akechi 2010)

Early identification of unmet needs/ risk of needs is a way to optimise care

(Armes 2009; McDowell, 2010; Stanton 2006)

institutCurie

What is necessary to implement a screening program of distress and supportive care needs ?

Requiered competencies

Many screening designs have been tested in the last decade, searching for a personalized answer to each patient 's unique needs

(Mitchell 2010, 2011, Carlson 2012)

* Eliciting sensitive and easy-to-use instruments
* Training health professionals (a big deal !….)
* Having an appropriate care organisation to refer patients presenting specific needs
* Being able to evaluate the global screening process
* Development of clinical guidelines allowing for the diffusion of good practices

institutCurie

IV- How to cope with the gap between « ideal world » and the real daily life ?

institutCurie

Showing 1 local example done at Institut Curie

Screening for distress and supportive care needs at the diagnosis time

institutCurie

1. Screening for distress and needs at the diagnosis time

Principal aim :

To evaluate the feasibility of implementing a systematic procedure of distress and supportive care needs' screening, managed by clinical nurses

Secondary :

- To collect descriptive data on : distress' prevalence, number and type of reported problems, type and adequacy of referral to Supportive Care Units

- To collect a feed-back from the nurses about the procedure

institutCurie

Organisation of the initial phase of the care process : the Therapeutic Decision Consultation (TDC)

* When ?

In the 7-10 days following the surgeon's post-surgical final diagnosis

« Personalized Program of Treatment »

Taking advantage of our Diagnosis Disclosure Procedure from our First National French Cancer Plan (2003-2007)

* How ?

Multidisciplinary consultation :

- **meet both the chemotherapist and the radiotherapist**
- **and then meet the nurse specifically dedicated to this TD Consultation** (as defined in Plan Cancer I)

--> Discussing the given medical information and explicitating treatments

--> Responding to patient's and caregiver's questions

--> Evaluating patient's supportive care needs

institutCurie

Two parts :

1 - Helping the nurses to identify problems to be referred to the Supportive Care Department

During the nurse interview of the TDC, 3 phases :

- **Self-evaluation** : PDS + problem checklist
- Nurse clinical interview (semi-structured)
- Nurse-**(hetero)**-evaluation and referral when necessary

2 - Nurses training :

Regular debriefing meetings, discussion of difficult clinical cases, medical chart analysis

institutCurie

French Validation of the NCCN Distress Thermometer

(Dolbeault 2008)

(cut off > 3, sensitivity = 0.75; specificity = 0.83)

Dans le contexte de la maladie, il arrive fréquemment de se sentir fragilisé sur le plan psychologique, que ce soit en rapport avec la maladie elle-même ou pour d'autres raisons personnelles.

L'échelle ci-dessous représente un moyen d'apprécier votre état psychologique.

Nous vous demandons de mettre une croix sur la ligne à l'endroit qui correspond le mieux à votre état psychologique de la dernière semaine.

Détresse très importante

Pas de détresse

institutCurie

Self-Evaluation : Problem list and Psychological Distress Scale

Document à remplir par le patient

Identité patient :

institutCurie

Département
Inter-Disciplinaire de Soins de Support du Patient en Oncologie

Madame, Monsieur,

Dans le contexte de votre maladie, il est possible que vous ayez repéré ou déjà rencontré un certain nombre de difficultés, qu'elles soient d'ordre pratique, physique, familial, psychologique...
Il vous est possible de nous en faire part au moyen de ce questionnaire. Celui-ci permet de préparer la consultation avec l'infirmière, au cours de laquelle les différents problèmes soulevés pourront être repris et une orientation vers les professionnels concernés pourra être envisagée.

En vous remerciant par avance de votre participation,
Bien cordialement,

L'équipe du D.I.S.S.P.O

Cochez les cases correspondantes. Après avoir rempli ce document (recto-verso), remettez-le à l'infirmier(ère) au début de la consultation infirmière.

Problèmes pratiques avec :	OUI	NON
- Logement	☐	☐
- Financiers (emprunts, assurances, etc..)	☐	☐
- Travail – Ecole	☐	☐
- Logistique (garde d'enfants, besoin d'aide à domicile etc..)	☐	☐

Problèmes physiques de :	OUI	NON
- Douleur	☐	☐
- Fatigue	☐	☐
- Sommeil	☐	☐
- Alimentation	☐	☐

Problèmes familiaux avec :	OUI	NON
- Conjoint	☐	☐
- Enfants	☐	☐
- Autres	☐	☐

Problèmes psychologiques de :	OUI	NON
- Soucis - préoccupations	☐	☐
- Tristesse	☐	☐
- Dépression	☐	☐
- Irritabilité	☐	☐

Autres problèmes Si oui, lesquels ? :	OUI	NON
	☐	☐

Tournez la page SVP →

D.I.S.S.P.O 10/2006 – Grille patient – dépistage d'annonce – orientation vers le DISSPO - SDV/IM/BB
Contact : secrétariat Tél : 01 44 32 40 96

L'échelle ci-dessous représente un moyen d'apprécier votre état psychologique.

Nous vous demandons de mettre une croix sur la ligne à l'endroit qui correspond le mieux à votre état psychologique de la dernière semaine.

Détresse très importante

Pas de détresse

Merci de dater le document

D.I.S.S.P.O 10/2006 – Grille patient – dépistage d'annonce – orientation vers le DISSPO - SDV/IM/BB
Contact : secrétariat Tél : 01 44 32 40 96

institutCurie

Caution !

The PDS score > 3 is **not** used as a direct referral criteria

It is considered by the dedicated nurse with other elements emerging from the clinical interview, taking into account the specificity of this initial phase of the care process

institutCurie

Exemple : Psycho-Oncology “minimum criteria”, Institut Curie

Critères / Unité	**CRITERES PLANCHERS** Minimum	**CRITERES IDEAUX** Maximum
Unité de Psycho-Oncologie (adultes)	. Idées, propos ou comportement suicidaire identifié . Antécédents psychiatriques lourds identifié (MMD, psychose) Refus de traitement ou défaut de compliance lié à un facteur psychologique . Conflit ouvert avec l’équipe soignante . Demande de suivi psychologique émanant du patient, de la famille ou de l’équipe	Adaptation du traitement psychotrope en fonction du traitement spécifique . Souffrance psychologique exprimée, jugée intense ou inadaptée par l’équipe soignante

institutCurie

Identité du patient :

GRILLE DE RECUEIL DE DONNEES
ORIENTATION VERS LE D.I.S.S.P.O

institutCurie
Ensemble, prenons le cancer de vitesse.

Identité soignant :

Date :

⇨CRITERES PLANCHERS DISSPO	⇔REPERAGE	⇨REMARQUES
Unité du Service Social	1= oui / 0 = non	orientation vers le service oui - non
. Moins de 20 ans		
. Plus de 70 ans, si : - entourage réduit et/ou conjoint + âgé à charge, - difficultés à se mouvoir - difficultés en lien avec les relations sociales		
. Personne dépendante à charge du patient		
. Isolement (pas de lien social ou familial)		
. Problèmes matériels (logement, emploi, ressources…)		
. Projet d'orientation médicale (demande de placement en cours)		
. Besoin d'aide à domicile		
. Unité Mobile d'Accompagnement et de Soins Continus	1= oui / 0 = non	orientation vers le service oui - non
. Situation palliative, dont l'accompagnement et/ou les problèmes symptômatiques sont jugés difficiles par l'équipe référente		
. Souhait de fin de vie à domicile exprimé spontanément par le patient et/ou son entourage		
. Réflexion éthique liée à la situation palliative (arrêt de traitement spécifique, sédation…)		
. Activité Plaies et Cicatrisations	1= oui / 0 = non	orientation vers le service oui - non
. Plaie chronique avec symptômes non contrôlés (odeurs, écoulement, hémorragies…) déjà pris en charge par l'équipe infirmière référente		
. Activité Addictologie	1= oui / 0 = non	orientation vers le service oui - non
. Demande de prise en charge spontanée d'une ou plusieurs addictions (alcool, tabac, etc)		
. Repérage soignant de signes cliniques de dépendance (alcool, tabac, etc)		
. Unité de Psycho Oncologie	1= oui / 0 = non	orientation vers le service oui - non
. Idées, propos, comportement suicidaire identifiés		
. Antécédents psychiatriques lourds connus		
. Refus de traitement ou défaut de compliance par rapport au traitement de la maladie cancéreuse		
. Projet de maternité		
. Activité d'Onco Gériatrie	1= oui / 0 = non	orientation vers le service
Attente validation des critères		
. Unité de Réadaptation Fonctionnelle	1= oui / 0 = non	orientation vers le service
. Immobilisation de la personne ou d'un membre > à 5 jours		
. Escarre		
. Respiration rendue difficile par des sécrétions audibles ou visibles sans examen clinique		
. Unité de Diététique	1= oui / 0 = non	orientation vers le service oui - non
. Perte de poids > à 10% en 6 mois - ou perte de poids >5% en moins de 1 mois		
. IMC<18,5 et IMC<21 pour les + de 70 ans		
. IMC > 30		
. Combinaison de plusieurs régimes ou régime mal adapté		
. Régime spécifique prescrit		
. Avant chirurgie gastrique, oesophagienne, résection du grêle		
. Avant gastrostomie		
. Département d'Anesthésie/Réanimation/Douleur	1= oui / 0 = non	orientation vers la cs douleur oui - non
. Douleurs post-chirurgicales avec EVA > à 3 ne répondant pas au Tramadol		

→

Cette grille à remplir par les soignants est un **outil de repérage** des besoins spécifiques des patients requérant les unités du D.I.S.S.P.O. ; Le Département Inter Disciplinaire de Soins de Support du Patient en Oncologie regroupe 5 unités, une cs d'addictologie et une cs infirmière : Unité du Service Social, Unité de Réadaptation Fonctionnelle, Unité de Psycho Oncologie, Unité Mobile d'Accompagnement et de Soins Continus, Unité de Diététique, une Cs d'addictologie et une cs infirmière Plaies et Cicatrisation. Chaque unité a défini les critères pour lesquels elle doit être sollicitée. Dans certaines spécialités, certains critères ont été grisés (ou hachurés) car non adaptés (NA).

Remettre le dépliant institutionnel du DISSPO avec coordonnées des services

Contact pour tout renseignement : secrétariat D.I.S.S.P.O tél. 01 44 32 40 98
Pour tout problème de compréhension d'un item vous pouvez vous référer à la Base "Bonnes Pratiques" sur l'intranet (Base de Connaissances) /services/consultations externes/orientation soins de support)

institutCurie

Population of new patients (N = 255)

representing 45 % of patients going through TDC

Age	
Median [Range]	59 [26-85]
Gender N (%)	
Female	234 (91,8)
Male	21 (8,2)
Cancer diagnosis N (%)	
Breast	209 (82)
Lung	41 (16,1)
Gynaecology	5 (2)
Stage N (%)	
Locoregional	235 (92,2)
Metastatic	20 (7,8)

institutCurie

Distress levels

PDS score N=255	
Median [Range]	2,7 [0-10]
PDS score > 3 N (%)	110 (43)
B y gender N (%)	
Female	106 (96.4)
Male	4 (3.6)
By stage N (%)	
Locoregional	101 (91.8)
Metastatic	9 (8.2)

institutCurie

Declared problems (self-evaluation)

Number of reported problems :

Pratical : 0 for 76 % patients, 1 for 16%, >2 : 7,5%
Physical : 3 x 33 % (0, 1, 2)
Family : 0 for 84 %, 1 for 14%
Psychological : 0 for 32 % patients, 1 for 34%, 2 for 20 %
Others : 1 for 14 %

Patients reporting ≥ 1 problem(s) N (%)		
	All patients (N = 255)	Patients with PDS >3 (N = 110)
Practical	60 (23.6)	29 (26.4)
Physical	178 (69.8)	84 (76.4)
Family	40 (15.7)	22 (20)
Psychological	168 (65.8)	88 (80)
Others	26 (10.2)	14 (27)

institutCurie

Referral to the Units of the Supportive Care Department

Referral to supportive care units N (%)		
Social Service Unit	90 (35.3)	49 (44.6)
Psycho-Oncology Unit	50 (19.6)	39 (35.4)
Physiotherapy Unit	61 (23.9)	32 (29.1)
Nutrition Unit	4 (1.6)	2 (1.8)
Wounds Unit	0	0
Palliative Care Unit	0	0

Most common combinations :

Social Service and Psycho-oncology : 86 patients

Social Service and Physiotherapy Unit : 38 pts

Psycho-oncology and Physiotherapy Unit : 22 pts

institutCurie

Discussion (1)

Among our sample :

*** 43 % have a significant distress level (EDP > 3)**
(but over-representation due to the gender factor, majority of breast cancer)

*** Declared problems : physical (70 %) and psychological (66 %)**
Among the sub-sample of patients with EDP > 3 : 76% et 80 % respectively

*** The PDS cut-off was not considered as an isolated criteria, had to be integrated with diverse clinical criteria, in order to help nurses in their clinical judgement**

*** Referral to :**

Social Service Unit (35 %) ; when PDS > 3 : 44 %
Physiotherapy Unit (23, 9%)(but mostly information consultations)
Psycho-Oncology Unit (19,6 %); when PDS > 3 : 35 %

institutCurie

Discussion (2) : qualitative evaluation from the nurses

Large benefit of regular clinical meetings

Positive points :

- Helping clinical judgement
- Systematic procedure : screening tools / clinical interview
- Legitimation of the nurse's role / feeling more responsible ++
- Giving to the nurses more tasks to explore some fields (psychological, spirituality)
- Teaching of simple communication skills
- Satisfaction of patients is high

Difficulties :

- Resistance coming from some health professionals
- Changing of habits and behavior
- Depending on the will of surgeons

institutCurie

Limits

Not a representative sample

Only a photography at this point

No baseline point to evaluate the procedure efficiency

No quantitative data about nurses practise' changes

Work has been done mainly with the nurses, but we also need doctors to be involved

Hard work to change health professionals behaviors. Needs repetition and follow-up

institutCurie

What to do then ?

* Repeat the screening procedure at each step

To repeat the procedure at different time to get a follow-up of distress and patients'needs

(eg : beginning of chemotherapy, radiotherapy, end of treatments, follow-up consults)

* Train professionals and write guidelines

all health professionals should be involved, included **doctors** …

* Emphasize communication skills trainings

institutCurie

2. Screening for breast cancer patient's distress and unmet needs at the end of the treatment and in the follow-up period

Study on work

Recruiting 350 patients a the first remission consult

- Determine prevalence and type of unmet supportive care needs at the end of treatment (T1) and 4 months later (T2)
- Prospective analysis of psychosocial factors' role in evolution of supportive care needs and in PTG at T2
- Examine impact of a specific follow up consult/notebook given to each patient on supportive care needs (T3)

institutCurie

Explored themes

- Quality of life and emotional state (QLQ-30, HADS, EDP)
- Satisfaction with care (PATSAT)
- Relations and communication (MCC, ECR)
- Perceived Social Support (SSQ)
- Self Estim (RSES)
- Post- traumatic growth (PTGI)
- Unmet needs (SNCS)

institutCurie

Waited outcomes of this longitudinal study ?

* Identify physical/psychological difficulties and needs to be avoided if risk factors or protective factors are understood

* Identify factors supporting post-traumatic growth

* Adapt care to each patient's needs

institutCurie

Hopes and limits

institutCurie

Positive outcomes

Unmet needs at the end of the trajectory is predicted by unmet needs at the beginning

Screening strategies help to recognize patient's distress and needs

Optimizes quality of care

Develop adapted psycho-oncological interventions

Limitations

No evidence yet about the direct impact on psychological well being

Need to be repeated along the whole trajectory

Many efforts to be done, by the whole community of health professionals

Need for Medical training

Difficult to apply in routine

Theoretical questions

What are the relations between needs, quality of life and satisfaction with care ?

(Brédart and Dolbeault, submitted)

What are the relations between expression of needs and attitude of seeking for help ?

(Steginga 2008; Andrykowsky 2010 ; Beesley 2010; Merckaert 2010)

Factors related to seeking for help : psychological distress, perception of utility of supportive care; caregivers' attitude

(Lepore 2008; Steginga 2008; McDowell 2010,Baker Glenn 2011)

Post traumatic growth's track *(Cicero, 2009; Schroevers 2010; Scrignaro, 2011)*

A lot of work still to be done …

institutCurie

Contact :

sylvie.dolbeault@curie.net

institutCurie