Screening for patient’s distress and supportive care needs during the whole health trajectory: Is it a way to answer to our patient’s psychological disorders?

ECRS, Copenhaguen, september 17th, 2012

Sylvie Dolbeault, MD, PhD, psychiatrist
Chief of the Supportive Care Department
Institut Curie, Paris
France
A great thank you to Christoffer Johansen, our past president of IPOS, a great contributor to PO science, himself and his team

And to all members of ECRS scientific and organizing committees
Context

Not feeling very legitimate to speak about survivorship, being working inside an hospital mainly with patients under active treatment

BUT !

as the head of the Interdisciplinary Supportive Care Department of Institut Curie
- Which integrates diverse competences : psycho-oncology, palliative care, social work, nutrition, rehabilitation, addiction, tumour wounds, oncogeriatrics
- Working with many structures out of the hospital : oncology networks, health networks, patient’s associations etc

Giving you my view about what we can 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 ?

What’s about our responsibility to help professionals to anticipate as much as possible patient’s actual but also future needs ?

S.Dolbeault. ECRS 2012
Plan

I - Supportive care definition and aims

II - Screening distress and needs: what to do?

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

IV – How to deal with the gap between ideal world and real life?
Showing examples of my institution

  . screening for distress and needs at the diagnosis time
  . Screening for unmet needs at the end of the treatment

V- Hopes and limits
I - Supportive care definition and aims
Aims of Supportive Care (1)

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 psychological distress
Aims of Supportive Care (1)

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**
II - Screening distress and unmet needs: what to do?
Why is it important to screen distress?

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

  Notion of clusters


* **Not screening distress**:
  
  - Worse quality of life
    

  - Higher sensitivity to symptoms
    
    (Breitbart 1995)

  - Less satisfaction / care
    
    (Brédart 2001 et 2006)

  - More coping and compliance troubles
    
    (Mitchell 2006)

  - Heavier costs
    

  - Survival? Many contradictory studies
    
    (Watson 1999, Dalton 2002 et 2009)

* **Health professionals ability to screen distress is low**:
  
  many barriers to communication


→ **We have to organise screening procedures and develop simple screening tools to detect patients in distress**
Using « Patient Related Outcomes » in the daily practise

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


* Experiences with quality of life

Done by doctors and/or nurses

Touch screen Implementations
using CAT (Computer Adapted System)


(Petersen 2006, Smith 2007 et 2009)

* Experiences with distress

… Psychological distress as « the 6th vital sign »


(Bultz Carlson 2007, 2010)

* Experiences with patient’s needs

(Snyder 2007)
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 (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)

- instruments most commonly used: HADS, CES-D, BSI, GHQ …

- The NCCN Distress thermometer

(Mitchell)
Screening methods under progress ...

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

- Addition of a Needs Scale (Mac Lachlan 2005)

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

- Variation of distress cut offs
Screening for cancer-related distress: what’s the impact?

Screening tools do improve screening by health professionals; but what about the referral to appropriate resources? (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

S. Dolbeault. MASCC, June 2011
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
- Treatment
- Follow Up

*impacting Quality of Life* (Ganz 2005)
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

• Treatment
• Toxic side effects
• Body change, feminity, fertility, social role, féminité

Needs

• Physical functioning/daily life
• Find support to deal with side effects
• Psychosocial

(Harrison 2009; Montazeri, 2008; Rowland & Massie, 2010; Sanson-Fisher 2000)
Follow Up (1)

Difficulties

- Losing hospital reassuring effect
- Fear of recurrence
- Pain, fatigue, physical and sexual dysfunction, 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 »

But ... positive change can also occur

*Studies among breast cancer women*

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)
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)
Follow Up (2)

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)
III - What is necessary to implement a screening program of distress and supportive care needs?
Requeried 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
* 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

S.Dolbeault. ECRS 2012
IV- How to cope with the gap between « ideal world » and the real daily life?
Showing 2 local examples done in my institution

IV-1. Screening for distress and supportive care needs at the diagnosis time

IV-2. Screening for distress and unmet needs at the end of the treatment and in the follow up period (under work)
IV-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 feedback from the nurses about the procedure
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 National French Cancer Plan

* **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
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-evaluation and referral when necessary

2 - Nurses training:
Regular debriefing meetings, discussion of difficult clinical cases, medical chart analysis
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

(cut off > 3, sensitivity = 0.75; specificity = 0.83)
Self-Evaluation : Problem list and Psychological Distress Scale

<table>
<thead>
<tr>
<th>Problèmes pratiques avec :</th>
<th>OUI</th>
<th>NON</th>
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</thead>
<tbody>
<tr>
<td>Logement</td>
<td></td>
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<tr>
<td>Finances (argent, emprunts, etc.)</td>
<td></td>
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<tr>
<td>Travail - École</td>
<td></td>
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<tr>
<td>Logistique (garde d'enfants, besoin d'aide à domicile etc.)</td>
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<tr>
<th>Problèmes physiques de :</th>
<th>OUI</th>
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<tr>
<td>Douleur</td>
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<td>Fatigue</td>
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<td>Sommeil</td>
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<tr>
<td>Alimentation</td>
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<tr>
<th>Problèmes familiaux avec :</th>
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<tr>
<td>Conjoints</td>
<td></td>
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<tr>
<td>Enfants</td>
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<tr>
<td>Autres</td>
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<thead>
<tr>
<th>Problèmes psychologiques de :</th>
<th>OUI</th>
<th>NON</th>
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<tbody>
<tr>
<td>Soucis - préoccupations</td>
<td></td>
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<tr>
<td>Tristesse</td>
<td></td>
<td></td>
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<tr>
<td>Dépression</td>
<td></td>
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<tr>
<td>Irritabilité</td>
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<thead>
<tr>
<th>Autres problèmes</th>
<th>OUI</th>
<th>NON</th>
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Passez à la page SVP

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!
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.
Nurse evaluation:

Checking a list of « minimum criteria » which will require a referral
### Exemple : Psycho-Oncology “minimum criteria”, Institut Curie

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

Remettre le dépistage institutionnel du D.I.S.S.P.O avec coordonnées des services

Contact pour tout renseignement : secrétariat D.I.S.S.P.O N° 02 44 32 40 98
Pour toute question de compréhension d’un item vous pouvez vous référer à la base "Bases Pratiques" sur l’interact (Base de Connaissances) /services/consultations-externes/orientation-avant-support)
Population of new patients ($N = 255$) representing 45% of patients going through TDC

<table>
<thead>
<tr>
<th>Age</th>
<th>Median [Range]</th>
<th>59 [26-85]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender N (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>234 (91.8)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>21 (8.2)</td>
<td></td>
</tr>
<tr>
<td>Cancer diagnosis N (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>209 (82)</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>41 (16.1)</td>
<td></td>
</tr>
<tr>
<td>Gynaecology</td>
<td>5 (2)</td>
<td></td>
</tr>
<tr>
<td>Stage N (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Locoregional</td>
<td>235 (92.2)</td>
<td></td>
</tr>
<tr>
<td>Metastatic</td>
<td>20 (7.8)</td>
<td></td>
</tr>
</tbody>
</table>
Distress levels

<table>
<thead>
<tr>
<th>PDS score N=255</th>
<th>Median [Range]</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2.7 [0-10]</td>
</tr>
</tbody>
</table>

| PDS score > 3 N (%) | 110 (43) |

By gender N (%)

<table>
<thead>
<tr>
<th>Gender</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>106 (96.4)</td>
</tr>
<tr>
<td>Male</td>
<td>4 (3.6)</td>
</tr>
</tbody>
</table>

By stage N (%)

<table>
<thead>
<tr>
<th>Stage</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locoregional</td>
<td>101 (91.8)</td>
</tr>
<tr>
<td>Metastatic</td>
<td>9 (8.2)</td>
</tr>
</tbody>
</table>
## Declared problems (self-evaluation)

### Number of reported problems:
- Practical: 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%

<table>
<thead>
<tr>
<th>Category</th>
<th>All patients (N = 255)</th>
<th>Patients with PDS &gt;3 (N = 110)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practical</td>
<td>60 (23.6)</td>
<td>29 (26.4)</td>
</tr>
<tr>
<td>Physical</td>
<td>178 (69.8)</td>
<td>84 (76.4)</td>
</tr>
<tr>
<td>Family</td>
<td>40 (15.7)</td>
<td>22 (20)</td>
</tr>
<tr>
<td>Psychological</td>
<td>168 (65.8)</td>
<td>88 (80)</td>
</tr>
<tr>
<td>Others</td>
<td>26 (10.2)</td>
<td>14 (27)</td>
</tr>
</tbody>
</table>
Referral to the Units of the Supportive Care Department

<table>
<thead>
<tr>
<th>Referral to supportive care units</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Service Unit</td>
<td>90 (35.3)</td>
</tr>
<tr>
<td>Psycho-Oncology Unit</td>
<td>50 (19.6)</td>
</tr>
<tr>
<td>Physiotherapy Unit</td>
<td>61 (23.9)</td>
</tr>
<tr>
<td>Nutrition Unit</td>
<td>4 (1.6)</td>
</tr>
<tr>
<td>Wounds Unit</td>
<td>0</td>
</tr>
<tr>
<td>Palliative Care Unit</td>
<td>0</td>
</tr>
</tbody>
</table>

Most common combinations:
Social Service and Psycho-oncology: 86 patients
Social Service and Physiotherapy Unit: 38 pts
Psycho-oncology and Physiotherapy Unit: 22 pts
Referral to Psycho-Oncology Unit: impact??

Among the 255 patients of our sample,

→ 50 are considered by the dedicated nurse as in psycho-oncological need and referred to the PO Unit

→ 21 had at least one PO consult:
  - 11 following the TDC
  - 5 other patients received one or more PO consult, but starting before the nurse did the referral (self-referral or done by another health care provider)
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%
Large benefit of regular clinical meetings

**Positive points:**
- Helping clinical judgement
- Systematic procedure: complementarity between 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
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
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 (e.g., 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
IV-2. Screening for distress and unmet needs at the end of the treatment and in the follow-up period

(under work)
Screening for breast cancer women’s needs at the post-treatment period

Protocol, currently being implemented at Institut Curie, Paris (2 sites)

*Funded by the French National Ligue against Cancer* (2010)

Chavie Fiszer ¹,²  
Anne Brédart ¹,²  
Sylvie Dolbeault ¹,³  

Brigitte Sigal ⁴  
Jean-Luc Kop ⁵  

(1) Psycho-oncology Unit - Supportive Care Department, Institut Curie, Paris  
(2) Laboratoire de Psychopathologie et processus de santé (LPPS EA 4057)  
(3) Université Paris Descartes  
(4) Oncology Department, Institut Curie, Paris  
(5) Université de Nancy II
Supportive Care Needs questionnaire

Many are available

We chose the Supportive Care Needs Survey (SCNS-SF34)

allows the patient to determine her specific needs and the degree of importance that each need has for her

5 domains:

- physical
- emotional
- patient care
- sexuality
- information needs

Adaptation and validation in French

(Snyder et al, 2009)

(Brédart, Kop, Dolbeault 2012)
Research questions

* Prevalence and intensity of needs among a breast cancer women cohort, at the entrance of follow up phase?

* Which factors influence evolution of these needs?
  - Sociodemographic, clinical
  - Psychological, psychosocial
  - In relation with care

* Which factors can help the process of post-traumatic growth?
Objectives

• 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)
Methodology

Population

Breast cancer women starting the follow-up period

- >18 yo
- Non metastatic breast cancer
- Having received surgery + chemotherapy, radiotherapy; receiving or not hormone treatment

350 patients to be recruited within 1 year

Institut Curie (Paris and St Cloud)
Data collection

- Clinical data: medical chart
- Questionnaires: 45 minutes

Timeline:
- T1: End of treatment
- T2: After Follow-Up consultation
- T3: 4 months
- 0: 8 months
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)
Statistical analyses

Descriptive analyses at T1, 2, 3

Multiple regression to analyse weight of each variable on supportive care needs’ evolution

- sociodemographical factors
- psychosocial factors (distress, functioning, quality of life, satisfaction with care, communication skills)
- factors related to the care system
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
V - Hopes and limits
**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 about the 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

Difficult to apply in routine
Theoretical questions

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

(Brédart, 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; Schroevres 2010; Scrignaro, 2011)

A lot of work still to be done …
Contact:
sylvie.dolbeault@curie.net

... this woman is not me,

but Marie Curie ...