Is respite care a reality? A french experience at the Marie Curie Institute among adult patients.

E.L. Angellier *, L. Bozec* , A. Vasseur *, C. Bouleuc**
*DISSPO Curie Saint Cloud 35 rue Dailly 92210 Saint Cloud/ **DISSPO Curie Paris
rue d’Ulm 75006 Paris. France
Abstract MSCC8-0730

Faculty Disclosure : nothing to disclose

Introduction : Respite is necessary for families with a severe cancer patient at home who requires complex care. Do we use it properly?
Objective : to investigate patients outcome after admission for respite care.
Methods : retrospective analysis of 18 months requests
Results : 24 requests addressed to palliative care units (PCU) called “respite”
None have had before a respite hospitalization
2 patients were refused by (PCU). Among 22 others : .
3 patients were unknown of our department of supportive care,4 have seen one of us during their last month and 15 had an early support. First contact with our DISSPO was medical (9) dietician (6) social (4) psychological (2) physiotherapist (1). 3 did not meet a doctor of the department.
11 used to live alone (divorced, widowed, single) which is not the proportion expected in our population or with these diseases.
Primary cancer : lung (4), ovarian (4), breast (4), others (10).

24 patients *	Severe symptoms	Family or loved ones respite	Median age	Median delay (request-admission)	Median length of stay
5 men, 19 women	4	20	70,5 (46-89)	3,5 days (1- 33)	21 days (1-62)**

*For 4 caregivers and patients were informed that it could be transformed in definitive stay until death
**19 if we exclude patients who were discharged, 21 for these latter ones (10 to 24)
The one who stayed 62 days had a intrathecal pump, and was difficult to discharge.

4 patients went back home:
- 1 is alive, 24 months after request
- 1 old woman was hospitalized after 3 days at home: sons could not cope anymore and expressed a need for hospitalization until death. She died 3 months after request and never came home again
- 2 went back home and died 3 and 5 months after request
= For these patients we can talk of respite...

Discussion:: If we use an opinion poll (1) 80 % of french people would like to die at home, but in contrary 60% die at hospital , and 25% at home.
30 days before dying 30 % of patients are at hospital, and 60% the day before dying. One crucial question in France is to find a way to help loved ones not to be exhausted. To anticipate the difference between « stay at home as long as possible » and « die at home » during discussion with patients and loved ones is also crucial and needs time.

In mirror a french law (28 december 2015) on the ageing introduced a right to respite for natural helpers, under conditions. But none of that exists in oncology, despite number of patients at home with natural helpers...and number of elderly patients

Conclusion : It remains difficult to assess time of End-Stage by vulnerable cancer patients who can quickly worsen. Maybe is the word *respite* not appropriate? We face with deliver bad news in the best timing as possible, including psychological timing of patients, caregivers, and families or loved ones. Patients’information level has to be transmitted to palliative care units, and help them to turn the stay as a definitive one, especially because we can't hospitalize them elsewhere. We may also think more often and earlier to real respite hospitalization – which could permit sequences home/ hospitalization/ home... - so that – maybe - family could cope till the end at home? And we have also to question who is really able to do with dying at home.

We wanted to thank PCU who have admitted these patients :Notre dame du Lac, Puteaux, La Verrière , Jeanne Garnier, Jean Jaurès, Claire Demeure et Montfermeil