Psychological adjustment of patients with unresectable pancreatic cancer and their caregivers after the first chemotherapy cycle

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Lille, FRANCE 2024
MASCC/AFSOS/ISOO ANNUAL MEETING
JUNE 27-29 · SUPPORTIVE CARE IN CANCER

Context

PDAC's poor prognosis
- 2nd cause of death in 2030 [1]
- 10-20% operable in a curative-intent
- survival at 5 years : 13 %

Major adjustment challenge
- Patients :
  - very high anxiety and distress [2]
  - resources : social support / active coping, acceptance [3]
- Caregivers :
  - heavy functional and emotional burden [4]
  - concomitant distress, sometimes higher than patient [5]

No in-depth data on the experience of patients and their caregivers

Objective : explore patients' and caregivers' perceptions of their psychological adjustment and coping resources at the critical moment of the 1st chemotherapy assessment.

Methods

Exploratory, qualitative, bi-centric and dyadic design

Participants
- 19 patients / dyads from 2 oncology units of French university hospitals (in Lille and Villejuif)
- Inclusion criteria : unresectable PDAC, participate with a close volunteer 2 months after the diagnosis

Data analysis
- semi-structured interviews
- 15-step Braun and Clarke [6] reflexive thematic analysis / COREQ criteria

Ethics
- local ethics committee agreement (2021-A02689-32)

Results

Patient (P) characteristics
- 61 years old (avg)
- university degree (80%)
- inactive (70%)
- metastatic / stabilised (70%)
- no problematic distress

70% ♂

Caregiver (CG) characteristics
- 57 years old (avg)
- partner (84%)
- university degree (60%)
- inactive (60%)
- no problematic distress

74% ♀

5 themes + 12 sub-themes have been identified

3 themes have been explored

	/19 P	/19 CG
1. Psychological adjustment of patients	**19**	**17**
Psychological impact	**19**	**17**
Cognitive	16	9
Emotional	19	15
Behavioral	19	11
Social support for patients	**19**	**12**
Caregiver	15	18
Other family / relationships	17	11
Health professionals	13	8
Coping strategies	**19**	**9**
Active coping	19	7
Acceptance	15	5
Distraction	13	4

2. Psychological adjustment of caregivers	**10**	**19**
Psychological impact	**9**	**19**
Cognitive	1	8
Emotional	8	19
Behavioral	5	18
Social support for caregivers	**1**	**17**
Health professionals	1	14
Other family / relationships	0	14
Coping strategies	**7**	**19**
Acceptance	1	16
Active coping	2	16
Distraction	2	11

3. Dyadic adjustment*	**18**	**19**
Agreement	**15**	**19**
Cognitive: shared vision / needs ("realism", be positive)	5	15
/CG: shared disease ; cognitive empathy ; matching personalities		
Emotional: empathy, "reciprocal suffering" ; instant emotional connection	7	17
/CG: protect the other (take it upon oneself, break down outside the home)		
Behavioral: mutual support ; protect the CG (+ children), encourage him to live its life ; open communication, find the right distance ; closer links ; aligned coping / keep hope	13	17
/CG: distraction		
Disagreement	**11**	**15**
Cognitive: vision/personality mismatch (CG + pessimist, anxious, fragile)	8	12
/CG: more radical views (give oneself every means, continue chemotherapy, euthanasia) ; differents characteristics (P + naive, anxious) ; empathy vs sympathy		
Emotional: differing emotional regulation (CG suppression, "panic", mood depression)	6	6
/CG: proximity and "whipping boy" ; distance the other ; reproach of being overly anxious		
Behavioral: misaligned behaviour /coping (excessive monitoring and care / "carelessness" on the part of the CG -> resistance on the part of the P -> tensions, conflicts	7	9
/CG: unmatching rhythms / strategies (P distraction vs CG acceptance, P disengagement vs CG active coping or positive reappraisal)		

*black: P + CG's views / pink: additional CG's comments

> *There are times when I'm in too much pain and he feels sorry for me. Gloria, 71*

> *I see her suffering and it hurts me. Fred, 70 (Gloria's husband)*

> *Her support is important, but she overdoes it. She doesn't think about herself at all and gets depressed. I'm a bit worried. Yannis, 66*

> *There are times when he wants to confront this alone and that's normal. It's quite difficult for me because I worry about him. Monica, 46*

Discussion

Patient adjustment
- major challenge but not as globally negative as in quantitative studies [7]
- highly dependent on various factors (e.g. time in cycle / medical results ; coping strategies) [3]

Caregiver adjustment
- distress sometimes more intense confirmed [5] (e.g. emotional "roller coaster" like patient)
- social support indispensable vs +/- heavy burden [4] ; various coping strategies, shared with patient [8 / 9]

Dyadic adjustment
- **Agreement** : confirmed "reciprocal suffering" [8] vs a shared disease ; matching views and mutual support sometimes to the detriment of the patient's needs.
- **Disagreement** : differences in perceptions (pessimism vs. denial) and emotional regulation, sometimes leading to tension / conflicts

Limitations
- patient population : over-representation of young men in couples, compared with French epidemiological data [10]

Conclusion

1st dyadic qualitative study on the experiences of inoperable patients and their caregivers after the 1st chemotherapy assessment

Research implications
- mixed and longitudinal studies to define the determinants of individual and dyadic +/- adaptive adjustment

Clinical implications
- systematic (re)assessment of psychosocial needs -> potential targeted interventions for patients / caregivers / couples

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