

PRO/QOL The patient perspective (1)

Laureline Gatellier

Japan Brain Tumor Alliance (JBTA)

Rare Cancers Japan (RCJ)




Laureline Gatellier, PhD, MBA

Advocacy Background



2016

- 10.2016: member of Japan Brain Tumor Alliance (JBTA)
- 11.2016 : attendance to SNO – Arizona, US 

2017

- 02.2017: speaker at JBTA meeting, Tokyo JP
- 05.2017: **1 article** in International Brain Tumour Alliance (IBTA) magazine
- 05.2017: **board member of JBTA**
- 07.2017: **board member of RCJ**
- 08.2017: represent JBTA at Japan Cancer Forum, Tokyo, JP 
- 09.2017: represent RCJ at Rare Cancer Europe at ESMO Madrid, Spain
- 09.2017: attend Survivor Scientist program (SSP) at JCA, Yokohama, JP
- 10.2017: attend IBTA summit in London UK 

2018

- 01.2018: represent JBTA at FFJCP in Tokyo, JP
- 02.2018: Patient days, EORTC, Brussels, Belgium 
- 03.2018: RCE/RCJ meeting, ESMO, Brussels, BE
- 04.2018: SSP at AACR, Chicago, US 
- 05.2018: **Elected president of JBTA**
- 05.2018: **3 articles** in IBTA magazine
- 08.2018: consult NCI specialists on PRO, US 
- 08.2018: represent JBTA at JCF, Tokyo, JP

Professional background

- 07.2018 – present: NCC
- 11.2005 – 06.2018: Pharma industry
- 04.2000 - 10.2005: Academia (incl. Master & PhD)

In
Japan

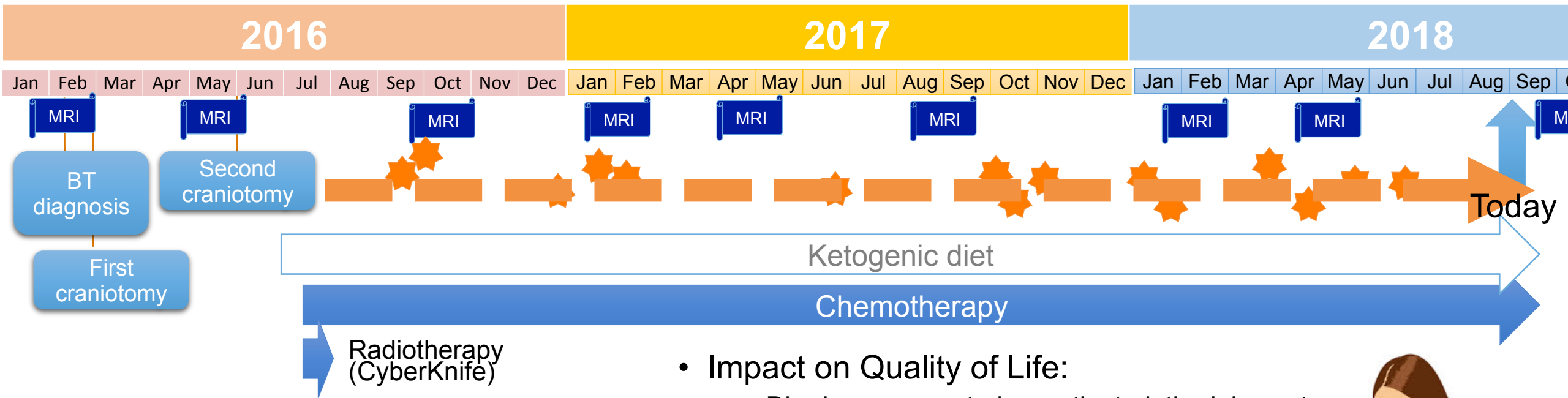


Agenda

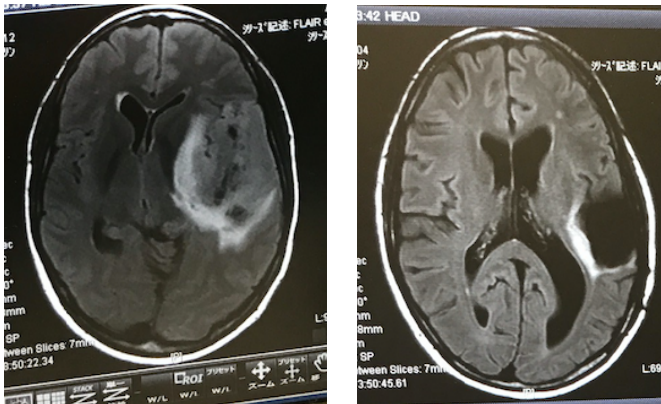


1. The Patient Experience – Brain Tumor
2. Why tracking of symptoms and QOL is essential
3. Use of PROs in Japan
4. Future and expectations

The Patient Experience – Brain Tumour (BT)



- Current status: **stable** tumor



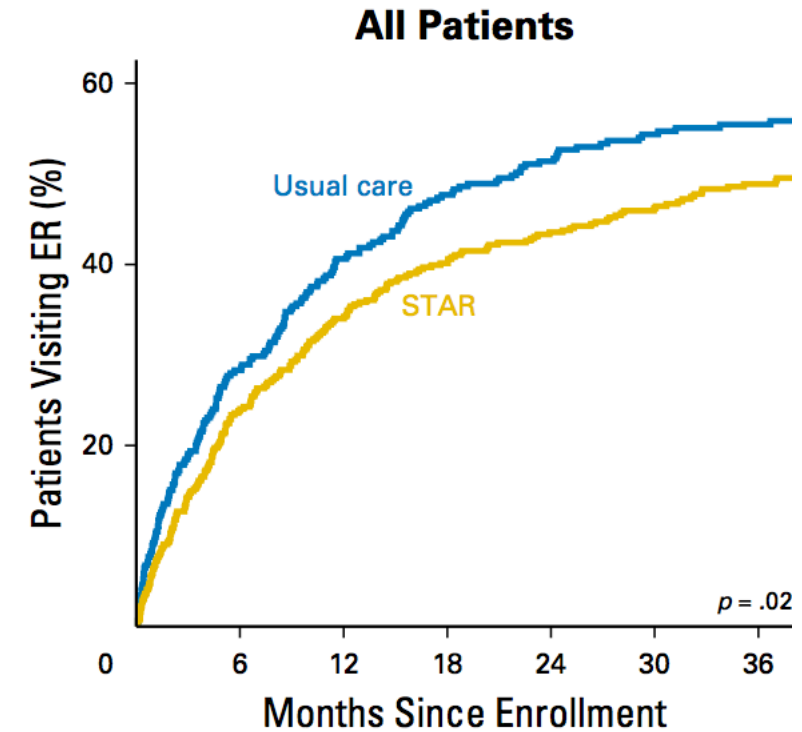
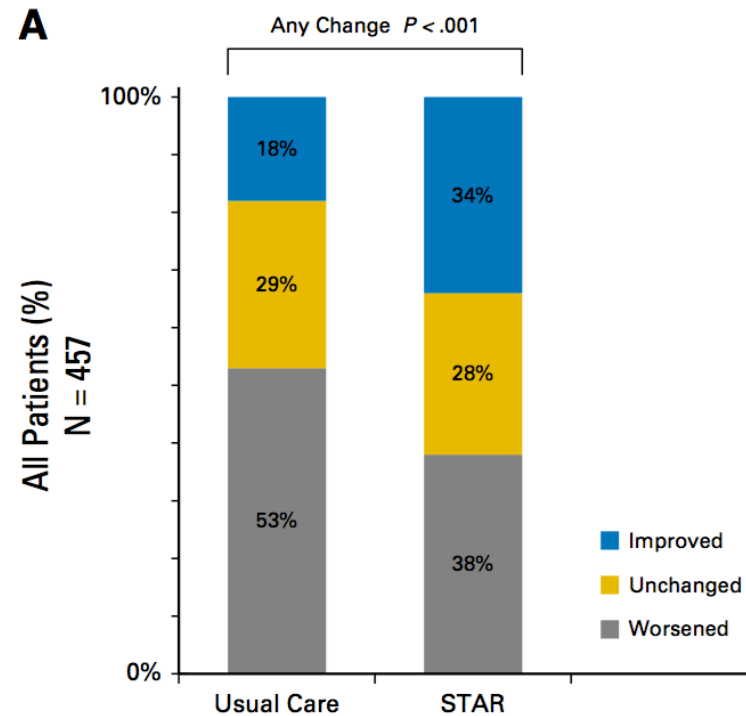
- Impact on Quality of Life:
 - Diarrhea, nauseated, constipated, tired, impact on family life and social activities
 - Tense / irritable / remembering things / concentrating
 - Uncertain about future
 - Seizures
 - Vision blurred
- Mid-Long term side effects – Chemobrain?
- Life expectancy?



Why tracking of symptoms and QOL is essential - Clinical Care



- Discordance between physician and patient reports
- PRO symptom monitoring with PRO during routine cancer treatment
 - Improved symptom control through systematic patient reporting
 - Fewer hospitalizations, superior quality-adjusted survival among others



Basch et al., *Lancet Oncol* 2006 7:903-909

Basch et al., *J Clin Oncol* 2016 34:557-565

<https://www.icrweb.jp>

Why tracking of symptoms and QOL is essential - New therapies and long term effects



- “Many molecularly targeted therapies and immunotherapies have AEs that are low grade, develop gradually and may become persistent and/or intolerable with sustained treatment”.
- PROs will be key combined with immunotherapies and genetic testing, as everyone responds differently to treatment
- PROs allow to compare two treatments
- PROs allow to evaluate long term impact of one treatment among individuals



Use of PROs in Japan Patient Perspective

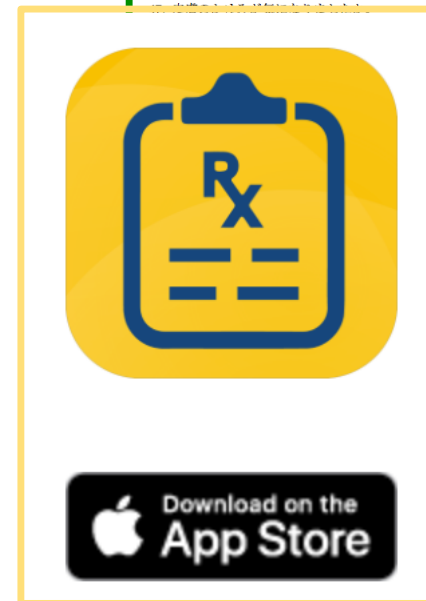
1. Tool prepared by patients and evaluated by specialists

Patients need it for their own tracking (incl. longer term assessment)

2. EORTC QLQ30 BN20

3. PRO-CTCAE

4. Available tools on the web: Cancer.Net



EORTC QLQ - BN20

患者さん達は、以下のような症状や問題があるとおっしゃることがあります。以下の点につき前の週にどのように感じたかお答えください。

最近1週間について:

	まったく ない	少し ある	多い	とても 多い
31. 将来に不安を感じましたか。	1	2	3	4
32. 体調が低下したと感じましたか。	1	2	3	4
33. 家庭生活が崩壊するような気がしましたか。	1			
34. 頭痛がしましたか。	1			
35. 将来の見通しが一層悪くなるように思いましたか。	1			
36. 物がだぶって見えましたか。	1			
37. 視界がくもりがちでしたか。	1			
38. 目の具合が悪く、読むのに不都合を感じましたか。	1			
39. 発作を起こしましたか。	1			
40. 体のどちらか半分側の力が抜けましたか。	1			
41. 何かを説明する時に適当な言葉が見つからず困りましたか。	1			
42. 話すのに苦労しましたか。	1			
43. 自分の意思を伝えるのに苦労しましたか。	1			
44. 昼間、眠くなることがありましたか。	1			
45. 手足がばらばらに動くような気がしましたか。	1			
46. 抜け毛が気になりましたか。	1			

NCI- PRO-

Item Library Version 1.0

がんの治療を受けている方は、しばしば異なる症状や副作用を経験いたします。それぞれの質問事項について、過去7日間にそれぞれの症状を経験されたかどうか、また経験された方は、その症状がどの程度だったか、もっとも自分の症状に過していると思われる回答に ×印をつけてください。

1. PRO-CTCAE™ Symptom Term: Dry mouth

口の中の乾き

Carrier 11:37 AM

Log a Symptom Cancel

What symptom are you experiencing?

Select a symptom from the list below:

Anxiety

Appetite Loss

Bleeding

Confusion or Delirium

Constipation

Depression

Diarrhea

Dry Mouth

Fatigue

Division of Cancer Control and Population
Sciences, National Cancer Institute, Bethesda, Maryland,
USA. For more information, please visit the
National Cancer Institute website.

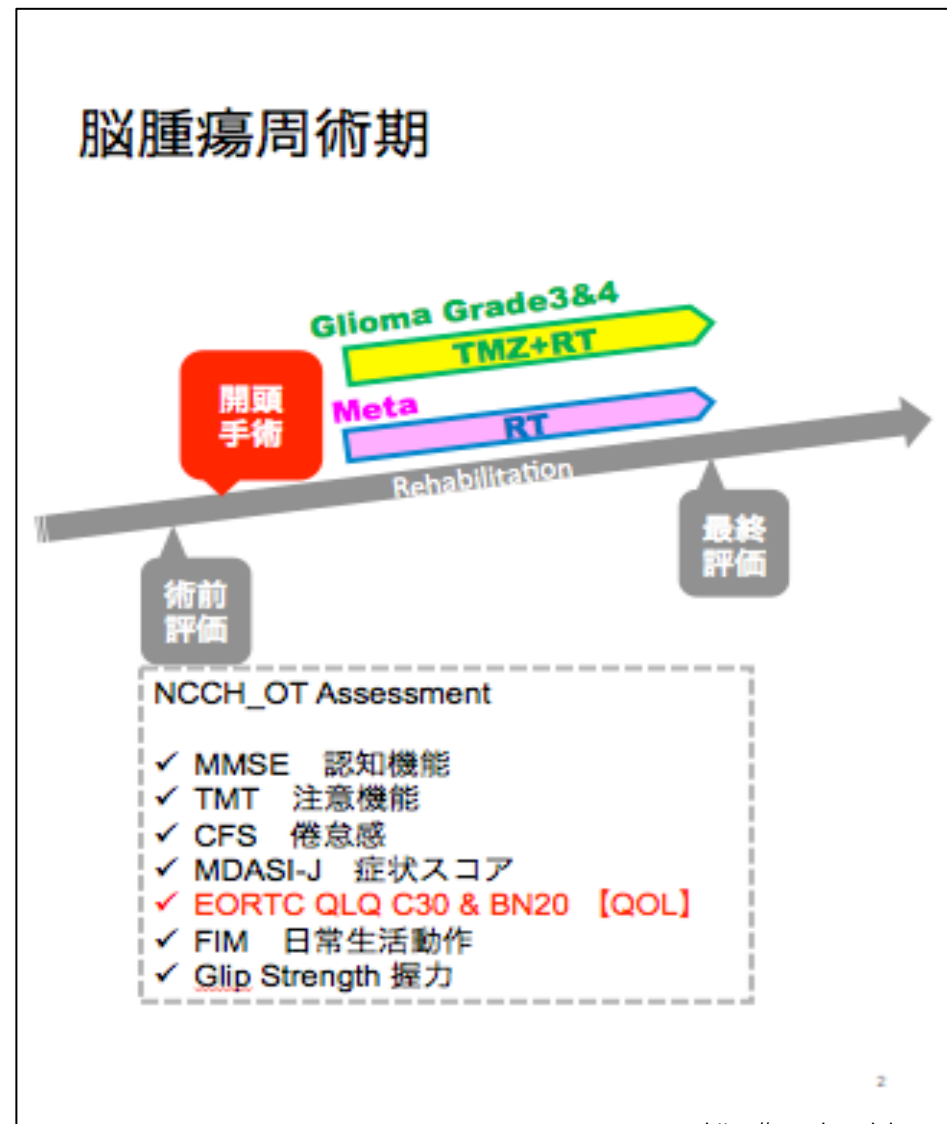


Use of PROs in Japan

Brain tumor concrete initiative



- Lead: Occupational Therapist
Takuro Sakurai
- Use of EORTC QLQ C30 and BN20 to compare QOL before and after treatment between primary and metastatic brain tumors
- 113 patients



3.2. Use of PROs in Japan Neurosurgeon perspective

*QOL assessment batteries, incl. PRO, are rarely used, not common in Japan
Rather, physician assessments are used, simpler, less time-consuming (e.g. WISC, K-ABC)*



Hurdles

- *lack of clinical psychologists*
- *Cost of QOL assessment: not attractive for hospital*
- *PROs not familiar in Japan*
- *BT is a rare disease*

Unfortunately I have never seen PROs (brain tumor patient-reported outcome) in Japan. In this aspect, Japan has been far behind EU/US.

If the patient uses a tracking tool like PRO, that will support my clinical practice! Please suggest it to BT patients!

Regarding PRO, I have no knowledge and idea. Sorry. But I think it is very important to analyze patients' satisfaction. If I understand what it is and feel necessity, I would to use it.

“KPS and “thermometers of distress and impediment” can be simple alternatives for QLQ-C30 and BN20”

The future and expectations of PROs/ e-PROs in Changing Landscape

A tracking tool like PRO is what I need!

I am too shy to explain my symptoms to my doctor.

This is an objective and regular tracking of my symptom in mid/long term.

Great form! I don't need to ask questions that will embarrass you! I will be glad to ask you focused questions as soon as we meet. I will scan and keep the data you brought.





Thank you very much for your attention.