

Coping with side effects of systemic anti-cancer treatment

patient-reported monitoring and subsequent interventions

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INTRODUCTION

Clinician-reported side effects, using CTCAE

- Severe (grade ≥ 3): focus on risk
- Moderate and mild (grade 1 & 2): Often not reported but impact of concurrent events can be substantial
- Mainly reported in RCTs, i.e. hardly any data about side effects from daily clinical practice
- Timing and type of symptom management & it's outcome generally understudied

Patient-reported side effects

- Focus on symptom burden & quality of life (QoL)
- PRO-CTCAE not yet common use

OBJECTIVES

garner experience from 3 European units on monitoring side effects to:

1. Enable (more timely) intervention
2. Enhance coping with side effects & self-management
3. Decrease short & long term side effects

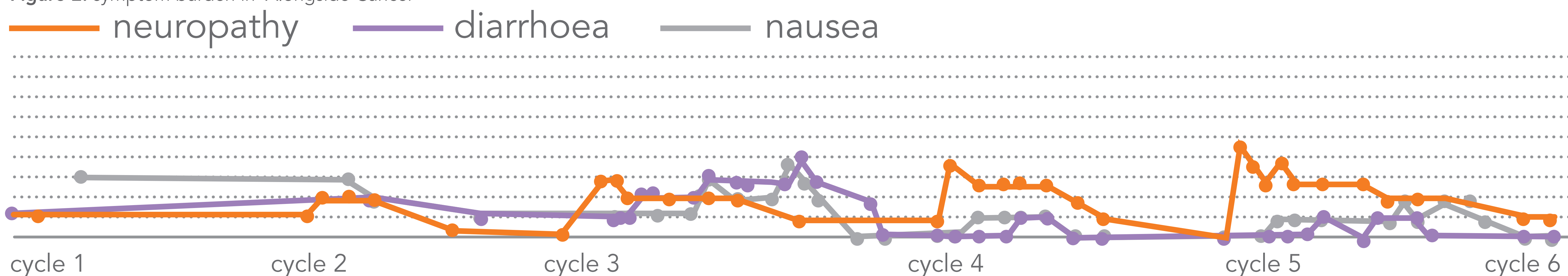
METHODS

- Dutch 'AlongsideCancer', UK 'Health Buddy@' & Belgian 'Symptom Diary' (figure 1)
- Home-based devices:
 - o Provide patient education
 - o Collect real-time data on side effects & QoL
 - o Feedback of data to patients & clinicians
 - o Patients instructed to call instantly in case of severe symptoms
 - o Send alerts to clinicians when exceeding a threshold

Figure 1: example of Symptom Diary

	day in cycle													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Less appetite or change in taste														
Not													x	x
My taste has changed or my appetite is less, but I do not need to change my eating habits					x	x			x	x	x	x		
I can eat less, but I do not lose weight	x	x	x	x			x	x						
I can not eat (enough)	x	x	x	x										
Fatigue, futility														
Not more than usual														x
I feel somewhat tired or futile, but I can perform my daily activities	x	x	x									x	x	
I feel quite tired or futile and some daily activities are hard to perform				x	x	x	x			x	x			
I feel so tired I can hardly perform my daily activities								x	x					

Figure 2: symptom burden in 'Alongside Cancer'



RESULTS

- 3 studies (NL n=60, UK n=71, BE n=302), variety of cancers

Patients

- Mainly positive, methods feasible
- Prefer to fill out only actual experienced side effects
- High variation in frequency of completing self reports
- Course of symptom burden is directly visible and predictable (figure 1 & 2)
- Helpful to set expectations for the next treatment cycle (coping)
- Facilitates patient-professional communication
- Completing diary as a way for getting good care (area of control)
- Report higher numbers & severity of symptoms compared to reporting at the next hospital visit

Healthcare professionals

- Sizable reduction in time investment
- Quicker & more complete insight, so immediate focus for symptom-management
- Urges to manage symptoms more actively
- Only effective if the patient is compliant
- Challenging implementation & integration within nursing team
- Positive patient experiences are condition for nurses to encourage self-reporting

Alerts

- 1247 high risk alerts due to 18 clinical symptoms, mostly distress (37.8%), rash or peeling skin (14.8%); lost of appetite (7.9%) & fatigue (7,4%)
- Skill mix required for phone calls by specially trained assistant clinical practitioner: mainly managing distress & comorbidities
- Details of 506 high risk alerts seen by the acute oncology team: 444 (88%) phone call only, 33 (7%) phone call & admitted, 25 (5%) phone call & emergency review in hospital

CONCLUSIONS

- Patient-reported side effects:
 - o are priority alongside clinician-reported side effects
 - o ensure improved communication with patients
- International standards required: accelerate knowledge transfer of real-time side effects, interventions & outcomes for patients & healthcare professionals
- Time to study incidence, timing and coping with side effects

