The PRIME framework for investigating emotions and other patient factors in low-intermediate risk prostate cancer patients based on online cancer support group discussions

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Abstract

Introduction and Objective
To use the Patient Reported Information Multidimensional Exploration (PRIME) framework, a novel ensemble of machine learning and deep learning algorithms, to extract, analyse and correlate self-reported information from online support group discussions (OCSG) by patients (and partners of patients) with low-intermediate risk PCa undergoing radical prostatectomy (RP), external beam radiotherapy (EBRT) and active surveillance (AS), and investigate its efficacy in determining Quality of life (QoL) and emotion measures.

Methods
All discussions related to low-intermediate risk PCa were extracted from ten OCSG with active user participation. A total of 390,071 online discussions by 6084 patients were analysed using the PRIME framework. Side effects and emotional/QoL outcomes were analysed.

Results
Side effect profiles differed between the modalities analysed, with men post-RP having more urinary and sexual side effects and men post-EBRT having more bowel symptoms. Key findings from the analysis of expressions of emotion; (i) PCa patients aged <40 expressed significantly high positive and negative emotions compared to other age groups, (ii) partners of patients expressed more negative emotions than patients, and (iii) selected cohorts (<40, >70, partners of patients) have frequently used the same terms to express their emotions which is indicative of QoL issues specific to those cohorts.

Conclusion
Despite recent advances in patient-centred care, patient emotions are largely overlooked, especially in younger men diagnosed with PCa and their partners. We present a novel approach, the PRIME framework, to extract, analyse and correlate key patient factors. This framework improves understanding of QoL and identifies those who require additional support in low-intermediate risk PCa patients.

Introduction

Treatment of low-intermediate risk PCa is becoming increasingly complex due to comparable cure rates of AS, RP and EBRT. Therefore, significant emphasis is placed on customising the side effect profiles of each treatment option to the patient.
Questionnaires completed in a 'trial setting' may not accurately capture 'real-life' issues experienced by patients.
Many patients utilize OCSG to freely express concerns related to their medical condition due to increased technology literacy, ease of use and a highly available virtual network of support.
Currently there is no method to accurately extract, analyze and correlate the wealth of implicit patient-reported information within this large body of unstructured text data.

Objectives

To use the PRIME framework, a novel ensemble of machine learning and deep learning algorithms, to extract, analyse and correlate self-reported information from OCSG by patients (and partners of patients) with low-intermediate risk PCa undergoing RP, EBRT and AS, and investigate its efficacy in determining Quality of life (QoL) and emotion measures.

Methods

The PRIME framework functions in two key stages; 1) OCSG selection and conversations filtering and 2) Patient-reported information extraction and analysis.
In stage 1, all discussions related to low-intermediate risk PCa were extracted from ten high usage OCSG with active user participation.
In stage 2, an ensemble of machine learning algorithms for classification, clustering and association rule mining, transform and enrich this linear extraction into a multidimensional data model pivoted by patient. This multidimensional data model consists of following patient-reported information; demographics, clinical information and expressions of emotion.
A total of 390,071 online discussions by 6084 patients were analysed using the PRIME framework. (Figure 1)

Results

Table 1 presents characteristics of participants and side effects experienced by those in each modality. Those undergoing RP had comparatively high urinary symptoms and sexual side effects compared to the other groups, while those who had EBRT had comparatively high bowel symptoms.

Figure 2a and 2b depicts the positive and negative emotion categories of five key age groups. PCa patients aged <40 expressed significantly high positive and negative emotions compared to other age groups.

Figure 3a and 3b presents positive and negative emotions categories by modality. Positive emotions are consistently expressed by all age groups of patients who received RP, where 'happy' is high among aged <40, and 'positive' is high among aged <40 and >70. However, in the same group, patients aged <40 are more 'afraid' and 'helpless' than other age groups. Patients who received EBRT express positive and negative emotions consistently. For AS, patients aged <40 are more expressive of all positive emotions, while, high in 'depressed', 'helpless' and 'confused' among negative emotions.

Partners of patients expressed more negative emotions than patients. Selected cohorts (<40, >70, partners of patients) have frequently used the same terms to express their emotions which is indicative of QoL issues specific to those cohorts. (Table 2)

Figure 1

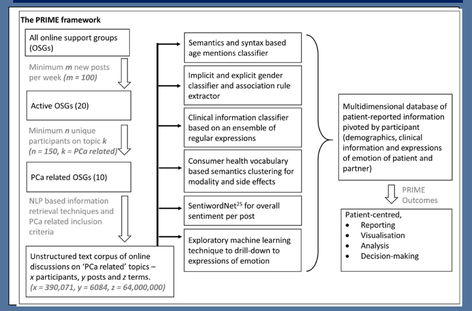


Table 1: Patient Demographics

	RP	EBRT	AS		
	n (% in RP)	n (% in EBRT)	n (% in AS)	n (% in Total)	p value
Total authors	4241	1528	315	6084	
Gleason score					
6	2543 (60)	831 (54)	269 (85)	3643 (60)	<0.001
7	1698 (40)	697 (46)	46 (15)	2441 (40)	<0.001
Median PSA	6	7.8	6.5		N/s
Age					
Age known					
<40	110 (3)	37 (2)	8 (2)	155 (3)	0.937
41-50	688 (16)	144 (9)	32 (10)	864 (14)	<0.001
51-60	1638 (39)	411 (27)	89 (28)	2138 (35)	<0.001
61-70	933 (22)	456 (30)	91 (29)	1480 (24)	<0.001
>70	197 (5)	192 (13)	39 (12)	428 (7)	<0.001
Unknown				1019 (17)	
Participant role known					
Patient	3702 (87)	1319 (86)	288 (91)	5309 (87)	0.676
Partner	539 (13)	209 (14)	27 (9)	775 (13)	0.069
Side Effects					
Urinary symptoms	2229 (53)	625 (41)	75 (24)	2929 (48)	<0.001
Bladder Irritation	804 (19)	407 (27)	32 (10)	1243 (20)	<0.001
Bladder neck contracture	586 (14)	196 (13)	17 (5)	799 (13)	<0.001
Urinary incontinence	1953 (46)	390 (25)	41 (13)	2384 (39)	<0.001
Urethral strictures	312 (7)	108 (7)	11 (3)	431 (7)	0.045
Bowel symptoms	84 (2)	98 (6)	1 (0)	183 (3)	<0.001

Fig 2: Positive and negative emotions by age group

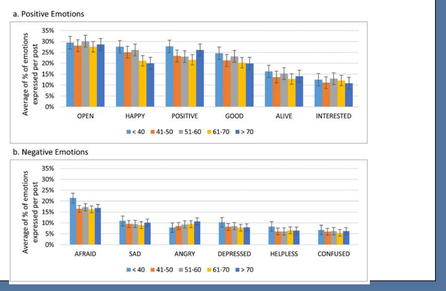
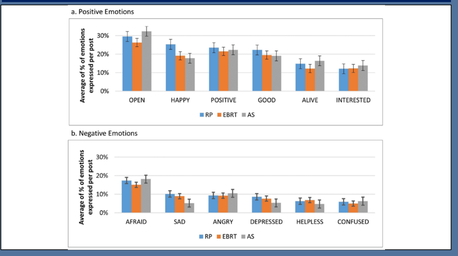


Table 2: Frequently used emotions for each age group

Group	Terms expressing positive emotions	Terms expressing negative emotions
Patients aged <40 (30% above baseline)	merry, lucky, intent, challenged, content, affected, loved, peaceful, brave, determined, pleased, tender, secure, reassured, wonderful	sore, fatigued, nervous, suspicious, frustrated, alarmed, bad, worried, frightened, scared
Patients aged >70 (10% above baseline)	reliable, accepting, touched, brave, courageous, satisfied, optimistic	unpleasant, threatened, frightened, fatigued
Partners of patients (20% above baseline)	quiet, spirited, reassured, loved, calm, admiration, brave, amazed, kind	tearful, upset, frightened, scared, guilty, worried, miserable

Fig 3: Positive and negative emotions by modality



Discussion

- PRIME framework provides an automated platform for the transformation of unstructured OCSG discussions into a structured multi-dimensional database of information.
- Patients aged <40 and partners appear to be the ideal beneficiaries of OCSG and could gain from additional health care resources and discussions focused on treatment decision making and cultivating positivity.
- While ,our results may have been influenced by selection bias, as we do not capture patients not using OCSG our cohort had similar charactserics and outcomes as other major studies1.

Conclusions

- Despite recent advances in patient-centred care, patient emotions are largely overlooked, especially in younger men diagnosed with PCa and their partners.
- We present a novel approach, the PRIME framework, to extract, analyse and correlate key patient factors. This framework improves understanding of QoL and identifies those who require additional support in low-intermediate risk PCa patients.

References

1. Bandaragoda T et al. Ann Surg Oncol. 2018 Feb 21
2. Ranasinghe W et al. BJU Int. 2017 Nov;120 Suppl 3:59-61.