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Letter

Open Notes in Oncology: Patient versus Oncology Clinician Views

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Beginning November 2, 2020, opening clinical notes to patients with cancer will no longer be a decision left to individual clinicians or institutional preference but rather a requirement, as a result of the 21st Century Cures Act Interoperability and Information Blocking Rule. The rule requires patients to be provided access to all health information in their electronic medical records, including progress notes (aka "open notes") (The Office of the National Coordinator for Health Information Technology, 2020). Cancer patients and their families face serious quality of life and information burdens that may be alleviated through access to notes (Blease et al., 2020). Earlier work has shown differences between clinician and patient attitudes after open notes implementation (Delbanco et al., 2010), but there has been no investigation into how oncology clinician views differ from those of their patients.

We analyzed data from two web-based surveys of clinicians and patients at three health systems and then used administrative data to identify oncology clinicians and patients (DesRoches et al., 2020; Walker et al., 2019). We included oncology clinicians with clinical service codes Doctor of Medicine (MD), Doctor of Osteopathic Medicine (DO), Nurse Practitioner (NP), Physician Assistant (PA), Registered Nurse (RN), and Physical Therapist (PT). All oncology clinicians contacted had at least one note read by a patient in the year prior to the survey. We identified cancer patients by applying the National Cancer Institute's ICD-10 diagnosis codes of reportable neoplasms to survey respondents who had opened at least one note in the past year (National Cancer Institute 2014). We then calculated response distributions for oncology clinicians and cancer patients on similar survey questions.

Among respondents, 96 clinicians worked in oncology settings, and 3,418 patients had a cancer diagnosis (Table S1). Compared with all other clinicians, the oncology group included a more diverse mix of credentials (49% were physicians). The majority of cancer patients were older than age 65, white, female, had more than a high school education, and spoke English as their primary language.

Most oncology clinician views about open notes differed from those of patients (Table S2). Seventy percent of clinicians agreed that open notes are a good idea, while 98% of patients endorsed this view. Twenty-eight percent of oncology clinicians agreed or somewhat agreed that notes could help patients be more prepared for their visits, while 56% of patients considered open notes as important for preparing (compared with 49% of all other patients). Further, 44% of oncology clinicians believed cancer patients would be confused by notes; just 4% of patients reported feeling confused after reading. Twenty-three percent of cancer patients said that they had contacted their provider's office about *something in their notes* in the past 12 months, and 89% of oncology clinicians found this happened infrequently (40% never contacted, 49% contacted less than once per month).

Patient and clinician views about open notes in oncology are not aligned, with patients expressing considerably more enthusiasm. Reading their clinicians' notes may particularly resonate with cancer patients who often face a greater information burden than other patients (e.g., multiple encounters, new terminology, new clinicians, complex treatment plans) that is easy to forget or misremember.

Results from this analysis are consistent with earlier work about clinician and patient views about open notes. There were few differences between the views of oncology clinicians and all other clinicians, which may suggest the type of specialty practiced bears little weight on the overall experience of sharing notes with patients.

The field of oncology should capitalize on the benefits that note sharing brings, e.g., help patients better remember next steps, prepare for future visits, and possibly avert unrealistic expectations. As the new rules about information blocking go into effect in November 2020, these findings should alleviate common concerns expressed by oncology clinicians and suggests organizational leaders be prepared with recommendations for sharing notes with patients and care partners to achieve the benefits of this transparency.

SUPPLEMENTAL INFORMATION

Supplemental Information can be found online at https://doi.org/10.1016/j.ccell.2020.09.016.

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Supplemental Information

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Supplemental Table S1. Clinician and patient respondent characteristics

CLINICIANS				
	Total (n = 1631)	***Non-oncology specialty (n = 1534)***	**Oncology specialty (n = 97)[a]**	**P value**
Year first licensed to practice	**No. (%)**	**No. (%)**	**No. (%)**	
Before 2000	591 (38.6)	*552 (38.3)*	39 (43.8)	.297
Year 2000 or after	940 (61.4)	*890 (61.7)*	50 (56.2)	
Hours per week in direct patient care				
<40 hours	1083 (70.6)	*1015 (70.2)*	68 (76.4)	.215
≥ 40 hours	451 (29.4)	*430 (29.8)*	21 (23.6)	
Sex				
Female	1,041 (65.1)	*979 (64.88)*	62 (69.66)	.357
Male	557 (34.86)	*530 (35.1)*	27 (30.3)	
Clinician type				
MD/DO	924 (60)	*880 (60)*	44 (49)	.004
NP	133 (9)	*125 (9)*	8 (9)	
PA	73 (5)	*73 (5)*	--	
RN/PT	420 (27)	*383 (26)*	37 (42)	

PATIENTS	**Total (n = 23576)**	***No cancer diagnosis (n = 20155)***	**Cancer diagnosis (n = 3418)**	**P value**
Age				
<45	6141 (26)	*5914 (29)*	227 (7)	<.001
45-64	9745 (41)	*8385 (42)*	1360 (40)	
65+	7687 (33)	*5856 (29)*	1831 (54)	
Sex				
Female	14855 (63)	*12951 (64)*	1904 (56)	<.001
Male	8718 (37)	*7204 (36)*	1514 (44)	
Race				
White	18300 (85)	*15413 (84)*	2887 (91)	<.001
Black	570 (3)	*508 (3)*	62 (2)	
Asian	1174 (5)	*1089 (6)*	85 (3)	
Other	729 (3)	*654 (4)*	75 (2)	
Multiple race	785 (4)	*725 (4)*	60 (2)	
Education				
High school or less	1456 (7)	*1218 (7)*	238 (7)	.021
Some college	4813 (22)	*4068 (22)*	745 (23)	
College graduate	7462 (34)	*6427 (34)*	1035 (32)	
Masters or Doctoral	8145 (37)	*6960 (37)*	1185 (37)	
Primary language other than English				
No	19963 (92)	*16937 (91)*	3026 (95)	<.001
Yes	1746 (8)	*1590 (9)*	156 (5)	

[a]*The total number of oncology clinicians does not add up to 97 due to missing data on the demographic variables.*

Supplemental Table S2. Oncology clinician views vs. cancer patient views of open notes

Clinician survey responses				Patient survey responses			
In general, making visit notes available to patients online is a good idea.				In general, making visit notes available to patients on {the patient portal} is a good idea.			
	Total	***All other clinicians***	**Oncology clinicians**		**Total**	***All other patients***	**Cancer patients**
	No.	No. (%)	No. (%)		No.	No. (%)	No. (%)
Disagree	155	*142 (9)*	13 (14)	**Disagree**	88	*78 (0)*	10 (0)
Somewhat disagree	266	*251 (17)*	15 (16)	**Somewhat disagree**	120	*108 (1)*	12 (0)
Somewhat agree	627	*592 (39)*	35 (36)	**Somewhat agree**	784	*681 (3)*	103 (3)
Agree	555	*522 (35)*	33 (34)	**Agree**	22399	*19136 (95)*	3263 (95)
				Don't know	182	*152 (1)*	30 (1)
In general, your patients who read their visit notes are better prepared for visits.				How important is reading your notes in preparing for your office visits? (Scale 0 [not important]– 10 [extremely important])			
	Total	***All other clinicians***	**Oncology clinician**		**Total**	***All other patients***	**Cancer patients**
Disagree	241	220 (18)	21 (26)	**0-7**	11166	*9705 (51)*	1461 (44)
Somewhat disagree	97	*89 (7)*	8 (10)				
Somewhat agree	213	*199 (16)*	14 (17)	**8-10**	11345	*9504 (49)*	1841 (56)
Agree	136	*127 (11)*	9 (11)				
Don't know	603	*574 (47)*	29 (36)				
In general, your patients who read their visit notes find the notes to be more confusing than helpful.				In general, how confusing were the visit notes? (Scale 0 [not confusing] – 10 [extremely confusing])			
	Total	***All other clinicians***	**Oncology clinicians**		**Total**	***All other patients***	**Cancer patients**
Disagree	123	*117(10)*	6 (7)	**0-7**	22055	*18853 (97)*	3202 (96)
Somewhat disagree	160	*148 (12)*	12 (15)				
Somewhat agree	263	*246 (20)*	17 (21)	**8-10**	756	*625 (3)*	131 (4)
Agree	242	*223 (18)*	19 (23)				
Don't know	501	*474 (39)*	27 (33)				
In the last 12 months, outside of office visits, how often did a patient contact you or your practice with questions about your notes?				Did you contact your provider's office about something in your visit notes in the past 12 months?			
	Total	***All other clinicians***	**Oncology clinicians**		**Total**	***All other patients***	**Cancer patients**
Daily, almost daily	10	*9 (1)*	1 (1)	**Yes**	4368	*3606 (19)*	762 (23)
Weekly	37	*33 (3)*	4 (5)				
Monthly (1-3x/month)	140	*136 (11)*	4 (5)				
<Monthly	538	*498 (41)*	40 (49)	**No**	16520	*14199 (74)*	2321 (70)
Never	574	*541 (44)*	33 (40)				
				Don't know	1701	*1469 (8)*	232 (7)
In the last 12 months, how many of your patients told you they were offended by something they read in a notes?				Have you ever felt offended by something you read in a visit note?			
	Total	***All other clinicians***	**Oncology clinicians**		**Total**	***All other patients***	**Cancer patients**

None	801	*754 (63)*	47 (58)	**Yes**	1810	*1546 (8)*	264 (8)
1-3 patients	414	*382 (32)*	32 (40)				
4-10 patients	60	*58 (5)*	2 (3)	**No**	21154	*18068 (92)*	3086 (92)
11 or more patients	11	*11 (1)*	0 (0)				