



# POST MORTEM MANAGEMENT OF SOCIAL MEDIA ACCOUNT IN PATIENTS WITH ADVANCED CANCER: WHAT HAPPENS AFTER DEATH?

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**Introduction:** Many cancer patients use social media actively. It is unclear if they have plans for their accounts after death. The objective of this study was to determine the proportion of patients with advanced cancer who have discussed the post-mortem management of their social media accounts with their family or friends.

**Methods:** In this one-time electronic survey, we enrolled adult patients with advanced cancer who self-reported any social media use and were seen at the outpatient Supportive Care Clinic at our tertiary cancer center. They were asked 10 questions regarding their plans for social media accounts after death. The primary outcome was based on the response to the following: “I have had conversations with my family/friends regarding how I would like any of my social media accounts managed after death.” Patients answered using a 5-point Likert scale from “strongly agree” to “strongly disagree.” “Agree” or “Strongly agree” were combined and considered as agreement.

Social Media Survey Statements	Agreement n (%)
<b>Communication of Post-Mortem Social Management</b>	
I have had conversations with my family or friends regarding how I would like any of my social media accounts managed after death.	24 (21)
I have discussed with family and friends how news of my death or a serious illness event may be shared on social media.	23 (20)
I have requested that friends and family do not share news of my death on social media.	8 (7)
I believe that my doctor should be able to answer questions about what may happen to my online or social media content after I die.	14 (12)
<b>Effects of the Social Media Use Survey</b>	
Talking about what happens to my social media accounts after I die has been difficult for me.	16 (14)
Completing this survey has increased my awareness of social media account management after death.	94 (82)
Completing this survey has motivated me to explore how my social media accounts will be managed after my death.	82 (71)
Completing this survey has motivated me to talk to my family about my social media accounts.	76 (67)
Completing this survey has caused me to have additional questions about what may happen to my social media accounts after I die.	25 (22)
I would like additional information about social media account management options.	11 (10)

Table 1. Post Mortem Social Media Survey

**Results:** Among 235 patients approached, 117 (50%) patients completed this survey. 24 (21%) reported that they discussed their preferences for management of social media after death (Table 1). 23 (20%) patients wanted their family and friends to share news of their death on social media, while 8 (7%) patients did not want to share. Hispanic ethnicity (29% vs. 8%, P=0.04) and low annual income <\$40,000 (57% vs. 21%, P=0.004) were associated with discussions about post-mortem management (Table 2). Upon completing the survey, 82 (71%) patients were motivated to explore their social media account managed after death and 76 (67%) would discuss this with their family or friends.

Variable		Have Had the Conversation N=24 n (%)	Have Not Had the Conversation N=92 n (%)	P-value
Age	Mean (SD)	55 (13)	57 (12)	0.57
Gender	Male	9 (38)	36 (39)	0.88
	Female	15 (63)	56 (61)	
Race/Ethnicity	Non-Hispanic White	13 (54)	69 (74)	0.04
	Black	3 (12.5)	10 (11)	
	Hispanic	7 (29)	7 (8)	
	Others	1 (4)	7 (7)	
Annual Household Income	<\$40,000	12 (57)	17 (21)	0.004
	\$40,000-\$80,000	4 (19)	17 (21)	
	>\$80,000	5 (24)	46 (58)	
	Unknown/Missing	3	12	

Table 2. Demographics of Primary Outcome from Social Media Survey

**Conclusion:** One in five patients had discussed post-mortem management of their social media accounts with friends or family, with higher rates among participants with Hispanic ethnicity and lower income. More research is needed to examine how social media may be considered as a form of digital legacy.

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