Valued Outcomes in the Cancer Experience: Patient Priorities and Control

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Background

- In the era of value-based cancer care, identifying what is important to cancer survivors, and their perceived control over these experiences, can inform shared decision-making and support quality care.

Aims

- The objective of this study was to examine cancer patient priorities and control to guide the development of a new measure of patient value, Valued Outcomes in the Cancer Experience™(VOICE).

Methods

- 459 cancer survivors completed an online survey, provided demographic and health history, and rated (0=*Not at all*; 4=*Very much*) their level of importance and control over 54 value items.
- Items of most and least importance (I), items with most and least control (C), and rating discrepancies (importance-control) were identified.
- Bivariate associations between items with high importance/control discrepancies and socio-demographic and clinical variables were assessed using ANOVA and pairwise post-hoc analyses.
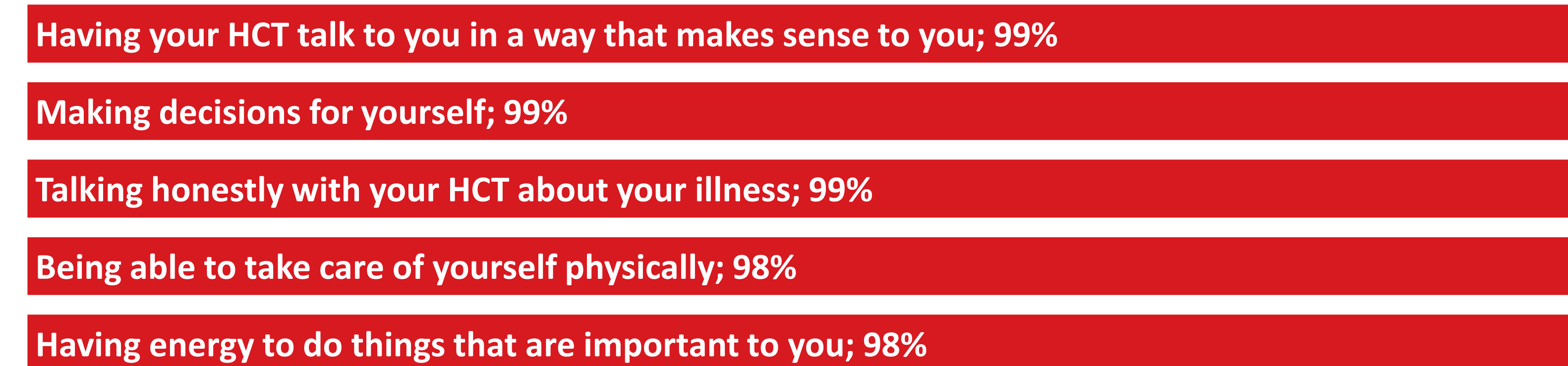
Participants

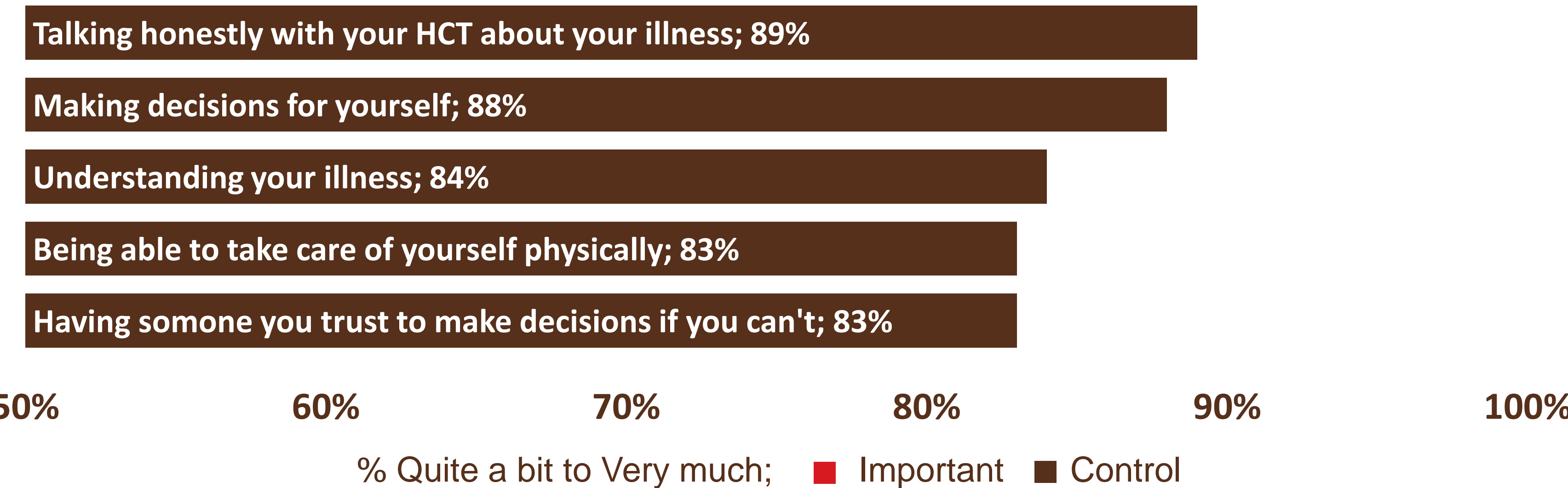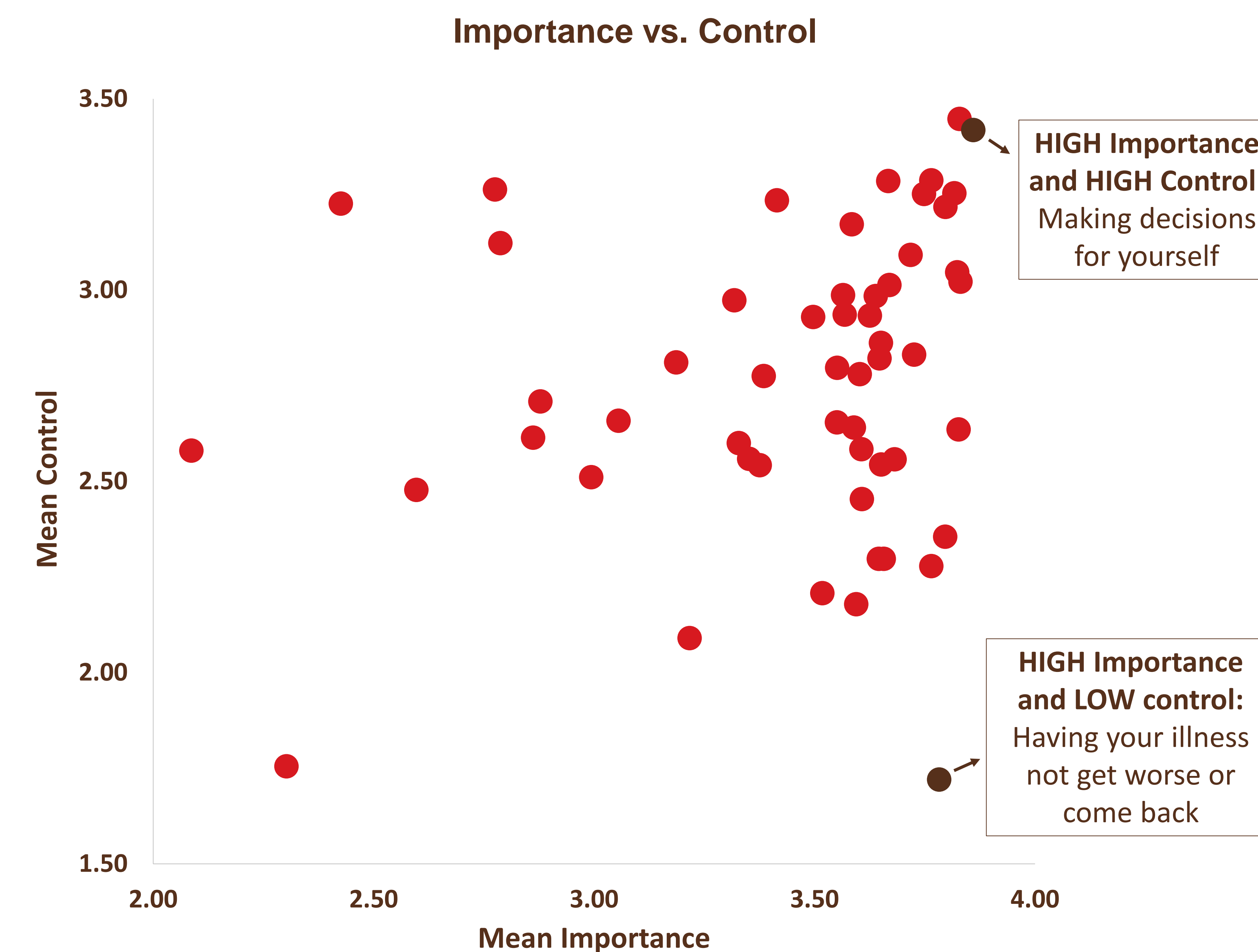| N = 459	Mean / n	SD / %
Age	60 years	10
	Range: 29 – 83 years	
Female	362	79%
Non-Hispanic White	384	86%
Diagnosis		
Breast	172	38%
Blood	81	18%
Lung	43	9%
Prostate	42	9%
Ovarian	20	4%
Other	101	22%
Time Since Diagnosis	6.5 years	5.5
	Range: 0 – 41 years	
Current Disease Status		
Metastatic	98	22%
Recurrence/Relapse	83	19%
Remission	239	54%
Treatment History		
Surgery	352	80%
Chemotherapy (past / current)	280 / 81	67% / 23%
Radiation therapy (past / current)	244 / 8	60% / 2%
Hormonal therapy (past / current)	106 / 87	29% / 24%

Results

Items of Highest Importance and Control

Highest Importance:

Having your HCT talk to you in a way that makes sense to you; 99%
Making decisions for yourself; 99%
Talking honestly with your HCT about your illness; 99%
Being able to take care of yourself physically; 98%
Having energy to do things that are important to you; 98%

Highest Control:

Talking honestly with your HCT about your illness; 89%
Making decisions for yourself; 88%
Understanding your illness; 84%
Being able to take care of yourself physically; 83%
Having somone you trust to make decisions if you can't; 83%

% Quite a bit to Very much; ■ Important ■ Control

- For each item, participants were asked, "Today, how <u>important</u> to you is…" and "Today, how much can you <u>control</u>…"

Importance vs. Control

HIGH Importance and HIGH Control: Making decisions for yourself

HIGH Importance and LOW control: Having your illness not get worse or come back

(Mean Importance vs. Mean Control)

Greatest Discrepancies between Level of Importance and Control

Items	% Important	% Control	Mean I-C	SD I-C
Having your illness not get worse or come back	96	27	2.05	1.34
Having energy to do things that are important to you	98	41	1.48	1.15
Being able to afford medical expenses	96	49	1.44	1.32
Having a death free from suffering	91	40	1.42	1.38
Having your medical providers communicate with each other about your care	94	44	1.36	1.31

- Mean/SD discrepancies are based on raw item ratings (0=*Not at* all; 4=*Very much*).

Associations with Greater Importance-Control Discrepancies

Items	F(df)	p
Having your illness not get worse or come back		
Poor general health	6.31 (4,424)	<.001
Having energy to do things that are important to you		
Low income	8.32 (2,444)	<.001
Unemployment, disability	7.93 (4,444)	<.001
Poor general health	16.09 (4,429)	<.001
Being able to afford medical expenses		
Low income	15.70 (2,440)	<.001
Unemployment, retired	9.07 (4,440)	<.001
Poor general health	10.13 (4,424)	<.001
Having a death free from suffering		
Unemployment, disability	3.51 (4,438)	<.005
Poor general health	5.43 (4,422)	<.001
Having your medical providers communicate with each other about your care		
Poor general health	6.06 (4,428)	<.001

- Greater discrepancies between level of importance and level of control were associated with lower income, unemployment due to retirement or disability, and poorer health.

Implications and Conclusions

- Cancer patients experience notable discrepancies between personal priorities and their ability to control these experiences.
- Areas for potential intervention include fear of recurrence, fatigue, financial and end of life issues.
- Interventions should be targeted towards patients with poorer health and fewer economic resources.
- Next steps include psychometric assessment to refine the VOICE scale to guide clinical and research efforts to improve patient care outcomes.

References

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