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Definitions of value among patients with breast cancer

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Background: Value in health care is the nexus of *best care* and *lowest cost*. How patients define value is key to measuring health care value in this era of shared decision making. Very little is understood about how patients define value and how disease stage may influence their attributions of value. We report on how persons diagnosed with metastatic (MBC) and non-metastatic breast cancer (non-MBC) define value. **Methods:** We asked registrants in the online Cancer Experience Registry: “When considering your cancer experience, how would you define value?” This analysis includes persons diagnosed with breast cancer who answered (n=651), comparing MBC (n=415) to non-MBC (n=236). (MBC response rate = 54%; non-MBC response rate = 49%.) Two researchers coded responses by categories, including: 1) personal benefit, 2) health care benefit. Subcategories are reported in Table 1. Interrater reliability was 90%. Table 1 shows responses by category for MBC and non-MBC. **Results:** Average age was 57 for MBC patients and 56 for non-MBC patients. Among those with non-MBC, 53% defined value as personal benefit. Among these patients, most defined value as a learned principle (42%; “Live each day to its best”). Findings are similar to patients with MBC for these sub-categories (Table 1). A nearly equal proportion of patients with MBC (28%) and non-MBC (29%) defined value in terms of health. Among those with non-MBC who defined value relative to health (n=68), most (43%) cited relationship with one’s health care team. **Conclusions:** These findings provide further support that patients may define value differently from HCPs, which may lead to a lack of alignment between HCPs and patients about what matters most in delivery of patient-centered care.

Table 1. Response by cancer type

Response*	MBC (n=415)	W/in MBC	Non-MBC (n=236)	W/in non-MBC
Personal	60.2%	n=250	52.9%	n=125
Practical	.72%	1.2%	2.9%	5.6%
Existential	21%	35%	14%	26%
Relational	11%	18%	13%	24%
Principle	24%	40%	22%	42%
Spiritual	3.6%	6%	.85%	1.6%
Health	28.4%	n=118	28.8%	N=68
Practical	6.2%	22%	11%	35%
Relational	8.1%	29%	12%	43%
Tx trade off	.48%	1.6%	1.6%	5.8%
QOL	9.1%	32%	2.1%	7.3%
Shared decision making	.72%	2.5%	2.5%	8.8%

*Remaining responses were unclear or stated not to understand