Preliminary Development of an Informational Media Use Measure for Patients with Implanted Defibrillators: Toward a Model of Social–Ecological Assessment of Patient Education and Support

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Social work interventions in health care, particularly those that involve working with people being treated for chronic and life-threatening conditions, frequently involve efforts to educate patients about their disease, treatment options, safety planning, medical adherence, and other associated issues. Despite an intuitive notion that patients access information about all of these issues through a variety of media—both inside and outside the clinical encounter, created by professionals and by others—there currently exists no validated means of assessing patients' use of these forms of information. To address this gap, authors first created candidate item measures with input from both physicians and a small group of diverse patients who currently have an implantable cardioverter defibrillator (ICD), a sophisticated cardiac device for which a trajectory model of social work intervention was recently outlined. Authors then surveyed a group of 205 individuals who have these devices, assessing their use of various media to learn about ICDs. They then conducted factor and item analysis to refine and remove poorly performing items while delineating forms of media use by type. The resultant preliminary measure of informational media use can be further refined and adapted for use with any clinical population.

KEY WORDS: *cardiovascular care; implantable cardioverter defibrillator; measure development; patient education*

Social work professionals and scholars in a wide variety of care venues are increasingly charged with health education, promotion, and other supportive roles for clients being treated with sophisticated medical interventions. Despite both an empirical (Fox, 2011) and a theoretical understanding that patients learn about their diseases and treatment in their social environment, investigations into social work processes in health care are hindered by a lack of quantitative measures assessing the venues through which medical patients actually learn about treatment. Treatment with an implantable cardioverter defibrillator (ICD) represents an excellent model through which to begin developing measures for use in social work research related to other invasive, technologically advanced treatments for life-threatening conditions.

A recent model for social work intervention with ICD patients (Knoepke & Johnson-Koenke, 2016) highlighted the importance of patient education across the care timeline, including during the initial decision to undergo ICD therapy, during acclimation to treatment, and during consideration of goals of care closer to the end of life. To date, no validated measures assessing the means by which patients learn about their medical treatments have been made available. Our goal was to address this gap by developing a measure of informational media use that delineates varied media by type. To accomplish this, we created candidate items for inclusion using the expertise of medical providers and the experience of current patients with ICDs, followed by an exploratory factor analysis (EFA) to reduce media use to continuous factors usable in

future research addressing patient education and support.

ICD BACKGROUND

Over the past 25 years, ICDs have gained in prominence and popularity as a first-line prevention measure for people at risk of sudden cardiac death (SCD), the leading cause of death in the United States and elsewhere (Heron & Tejada-Vera, 2009; Kong et al., 2011). Between the ICD’s demonstrated ability to improve survival rates among victims of ventricular arrhythmias (Antiarrhythmics versus Implantable Defibrillators [AVID] Investigators, 1997; Greenberg et al., 2004) and congestive heart failure (Bardy et al., 2005), the device is now implanted in more than 160,000 patients in the United States annually (Hauser & Almquist, 2008), including 50,000 in people over the age of 65 years (Kremers et al., 2013).

Extant research into quality-of-life (QoL) problems experienced by ICD patients (Godemann et al., 2004; Sears, Todaro, Lewis, Sotile, & Conti, 1999) and consistent support for the notion that information about treatment is a critical element to efforts meant to mitigate these risks (Habibović, Burg, & Pedersen, 2013) illustrate the need to understand how patients learn about device therapy. The fact that QoL risks are disproportionately borne by members of historically marginalized groups—including older patients (Hamilton & Carroll, 2003; Kramer et al., 2015), African Americans (Wilson, Engelke, Sears, Swanson, & Neil, 2013), women (Thylén, Dekker, Jaarsma, Strömberg, & Moser, 2014), and those with a history of life-threatening cardiac events (Pedersen, Hoogwegt, Jordaens, & Theuns, 2013)—highlights further the impetus for social workers to improve care for patients across the life span of ICD treatment.

METHOD

Informational Media Scale Development:
Two Subject Matter Expert Reviews

To begin developing informational media items, drafts of items for potential inclusion into both

measures were derived by the primary author with the guidance of professional subject matter experts, including two consulting cardiac electrophysiologists and a geriatrician with an extensive clinical and research history in defibrillator care and shared decision making. Candidate items for the informational media measure were adapted from content areas defined in Serber and colleagues’ (2009) assessment of group informational preferences, while aligning with as many levels of a socioecological conceptualization of information acquisition as possible (Bronfenbrenner & Morris, 1998).

Following initial item creation, these items were iteratively reviewed by three current ICD patients. Patients spoke with the first author for at least one hour each, providing individual feedback for each item in the new measure. These patients were diverse in both demographic backgrounds and type of insurance coverage held (see Table 1). Participants’ feedback included the addition of several forms of informational media (which they reported having used to learn about their device), a number of fact-based questions about ICD treatment, and clarifying language to include in survey items and directions. Following these interviews, the final version of the informational media measure was re-reviewed by the authors for clarity and clinical accuracy.

The resulting scale included 14 items assessing specific media through which patients may learn about their treatment. Each item is rated on a five-point Likert-type scale ranging from 1 = no information to 5 = a lot of information. Although informational media items were developed with specific attention to materials available to patients with defibrillators, they represent common elements of informed consent processes (Raab, 2004) and educational materials for a variety of medical treatments, including industry-developed informational brochures, commonly accessed Web sites, special interest newsletters (both online and in paper format), hospital-specific informational seminars and support groups, and consultations with care providers.

Table 1: Demographic Overview of Current Patient Informants				
Informant	Approximate Age	Gender	Race/Ethnicity	Type of Insurance Coverage
1	70	Female	Caucasian/not Hispanic	Medicare
2	20	Male	Hispanic	Private (through parent)
3	55	Female	Caucasian/not Hispanic	Canadian National Health Service

Participant Characteristics of Quantitative Survey

In total, 205 eligible patients being cared for through a major university-based medical center completed survey materials. A priori exclusionary criteria included patients not treated with an ICD (including patients with only the pacemaker function active), patients whose ICD had been removed (due to another device placement or heart transplant), patients who lack decision-making capacity, and patients who primarily communicate in a language other than English.

The respondent sample was sociodemographically diverse, with both African American and American Indian/Alaskan Native respondents being

moderately overrepresented when compared with the general patient population in this hospital system, and the proportion of female representation falling in line with other investigations into issues faced by this patient group (see Table 2). Participants were 60.7 years of age on average (*SD* = 14.53) and had been treated with an ICD for just under six years (*M* = 71.48 months, *SD* = 44.00); nearly three-quarters had been recommended ICD therapy as primary SCD prevention (73.7 percent). More than half (56.1 percent) have less than a bachelor's degree, and nearly a quarter (23.4 percent) live in a household with less than \$20,000 in annual income.

Table 2: Characteristics of Implantable Cardioverter Defibrillator (ICD) Survey Respondents (N = 205)				
Characteristic	M	(SD)	%	n
Age (years)	60.7	(14.53)		
Gender, male			65.9	135
Months since implant	71.48	(44.00)		
ICD indication (% primary prevention)			73.7	151
Ethnicity				
Hispanic			2.9	6
Non-Hispanic			90.2	185
White/Caucasian			81.0	166
Black/African American			10.2	21
Asian			2.0	4
Multiethnic			1.5	3
Native American/Alaska Native			1.5	3
Hawaiian/Pacific Islander			0	0
Other			3.4	7
Annual income (\$)				
0–20,000			23.4	48
20,000–40,000			14.1	29
40,000–60,000			17.6	36
60,000–80,000			9.3	19
80,000–100,000			6.8	14
100,000–150,000			11.7	24
More than 150,000			11.7	24
Education				
Less than high school			5.9	12
High school/GED			13.7	28
Some college			26.3	54
Associate's degree			10.2	21
Bachelor's degree			22.4	46
Master's/professional degree			16.6	34
Doctorate			2.4	5
Times shocked by ICD				
0			62.9	129
1–5			24.4	50
5–10			6.8	14
More than 10			5.9	12

RESULTS FOR EFA AND ITEM ANALYSIS

Principal components factor analysis with varimax rotation was used to reduce items on the informational media history measure to its simple structure. All informational media items featured low levels of missing data (all were below 2.5 percent, and eight of the 13 items were at 1 percent). To ensure that the factors chosen for retention accounted for an acceptable amount of variance (>60 percent), were composed of enough items to maintain sensitivity, and met a modicum of face validity (in terms of logical item groupings), this analysis limited the number of factors retained to those with eigenvalues greater than 1. Item analyses were then conducted on each retained factor (with at least three items) to maximize the internal consistency within each.

The initial EFA found five factors underlying the original 14 informational media items. These

factors were extracted in six iterations and collectively account for 67.1 percent of the total variance in reported informational media use (see Table 3).

Item loadings on identified factors were further analyzed to discriminate these factors from each other and to remove poorly performing items. To consider an item to be “loading” on a particular factor, the item must have had an observed loading of at least .5 on that factor and must not have loaded equally on any other factor (defined for this analysis as a difference of greater than .25 in absolute value of loading observed). As shown in Table 4, 12 of the original 14 items, covering all four identified factors, were retained following this process. Three separate two-item factors were identified and retained to maintain maximal amount of variance explained, and out of a recognition that the measure is intended to be used in brief clinical and

Table 3: Informational Media Factors Extracted in Exploratory Factor Analysis

Component	Initial Eigenvalues			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.855	27.534	27.534	2.541	18.150	18.150
2	1.696	12.115	39.649	1.900	13.572	31.722
3	1.521	10.866	50.515	1.823	13.018	44.740
4	1.228	8.772	59.287	1.641	11.721	56.462
5	1.101	7.863	67.150	1.496	10.688	67.150
6	.917	6.547	73.697			

Note: Extraction method: principal component analysis.

Table 4: Informational Media Item Loadings, by Identified Factors, Varimax Rotated Component Matrix

Factor	Component				
	1	2	3	4	5
1. Conversations with my doctor	.122	.076	-.015	.875	-.019
2. Conversations with my ICD nurse	.017	.098	.111	.850	.064
3. Advice from people who are not health care professionals (like family/friends)	-.013	.184	-.006	.016	.720
4. Conversations with a mental health professional (such as a social worker or a psychologist)	.170	.266	-.023	.058	.758
5. Paper brochures about ICDs (from hospitals or device companies)	-.102	.642	.075	.349	.143
6. Paper newsletters	.177	.858	.059	-.004	.118
7. Online newsletters	.515	.624	.099	.037	.123
8. Web sites about ICDs where I couldn't ask questions (like WebMD)	.804	-.108	.081	.143	-.068
9. Web sites where I could ask questions (like message boards)	.738	.087	-.017	.024	.238
10. Online videos made by other patients (like YouTube videos)	.623	.300	.414	-.073	.173
11. Online videos made by professionals (like doctors, hospitals, device companies)	.725	.159	.249	.023	.104
12. In-person support groups about ICDs	.131	.142	.901	.042	-.013
13. In-person educational meetings about ICDs	.173	-.027	.887	.082	.039
14. Other	.257	-.309	.131	-.004	.535

Notes: Extraction method: principal component analysis. Rotation method: varimax with Kaiser normalization; rotation converged in six iterations. Boldface = observed item loadings onto identified factors. ICD = implantable cardioverter defibrillator.

research encounters (in which parsimony, simplicity, and brevity are highly valued).

Internal item analysis was then conducted on the remaining individual factor with three items (factor 1, online patient information). In its original format, which addressed reported use of passive Web sites, active Web sites, and online videos made by professionals, the factor obtained a Cronbach's alpha of .682, which would have been reduced by the removal of any item (see Table 5). Two factors, (1) conversations with health care professionals and (2) use of in-person meetings, illustrated adequate internal reliability ($\alpha \geq .70$), and two more between $\alpha = .60$ and $\alpha = .69$ (paper patient information and online patient information). The remaining factor, advice from non-health care professionals, included only two items, had a very low reliability estimate ($\alpha = .47$), and was dropped from the scale and subsequent analyses.

A total of nine items contributing to four factors have been retained for use in future research. Total scores and variability were calculated for each of these informational media history domains (see Table 5).

DISCUSSION, LIMITATIONS, AND FUTURE DIRECTIONS

The media through which patients with ICDs learn about their treatment, and therefore the avenues through which social work interventions may be delivered, were defined along four primary lines: conversations with health care providers, paper patient information, online patient information, and in-person meetings. Although three of these factors were assessed using only two items (and are thus comparatively unstable), the brevity of the overall measure may hold value for research conducted in clinical environments (including hospitals, emergency departments, mental health centers, and so on), especially if this measure is adapted and further developed for other diseases and treatments. This development would

ideally include items addressing additional forms of media, as Spearman-Brown (Brown, 1910) analyses indicate an opportunity to improve reliability of observed factors, sometimes with as few as two additional items.

Problems observed in the reliability of the advice from non-health care professionals factor are of particular pertinence to future refinement and adaptation of this measure, and there are several possibilities for what may have contributed to this finding. Previously reported levels of psychosocial distress among this patient population (Bostwick & Sola, 2011) would seem to indicate a probability that patients would reach out to behavioral health professionals (including social workers) for information or support. Despite this probability, participants reported receiving very little information from these sources ($M = 1.25$, $SD = .69$), and the question assessing this venue of information acquisition performed so poorly as to not be viable for inclusion in further analyses. This particular outcome may also have been predictable given the relative paucity of formalized training provided to social work and other mental health professionals in working with patients being treated with complex medical therapies (Knoepke & Johnson-Koenke, 2016). Beyond this, however, there exists the possibility that patients may have accessed information from a social worker or other supportive professional, but in an environment they did not consider to be tied to behavioral health. Because social work support was only framed within the context of behavioral health, as it was in our items, reported levels of information received from social workers may have differed between patients who accessed social work support in a behavioral health context, those who accessed social work support in a different context but did not report this contact, and those who did not access social work support, with these differences attributable to reasons outside the psychometric construct of behavioral health support.

Table 5: Internal Reliability and Descriptive Statistics for Informational Media Factors							
Factor	Items	Cronbach's α	No. Needed for $\alpha \geq .80^a$	<i>n</i>	<i>M</i> (<i>SD</i>)	Min.	Max.
Conversations with health care professionals	1, 2	.70	2	202	7.84 (1.85)	2	10
Advice from non-health care professionals	3, 4	.47	7	N/A	N/A	N/A	N/A
Paper patient information	5, 6	.63	3	201	4.67 (1.90)	2	10
Online patient information	8, 9, 11	.68	3	202	4.69 (2.37)	3	15
In-person meetings	12, 13	.84	0	203	3.33 (2.17)	2	10

^aNumber of additional items, as determined using Spearman-Brown Prophecy formula; N/A = not calculated, as factor was removed.

More generally, the instability of this factor may also indicate that media not tied specifically to the medical encounter were underrepresented in the list provided. The language used to describe information acquisition behavior between survey items could have affected how participants endorsed use of these media. For example, all interactions with social workers, doctors, nurses, and other professionals were framed as “conversations,” whereas those involving other nonprofessional people were characterized as the reception of “advice.” The language used to describe the quality of the interactions should be carefully considered to ensure consistency in response across participants, who may interpret the value of these terms differently.

To address each of these issues, future investigations into informational media history should both develop a number of like items to test alongside those retained in the current measure, with a goal of increasing each factor’s reliability coefficient to at least .80, and delineate media tied to supportive services provided by those other than physicians and nurses to a greater degree than in the present example. These sources may include media that are specific to individual treatments or disease processes (for example, information provided to breast cancer patients by advocacy organizations), or ones that were simply overlooked in the present study. The addition of more questions addressing conversations with nonmedical professionals and static materials other than those available online may stabilize observed factors, and may provide additional context to social information acquisition among patients.

One such possible oversight with respect to informational media venues is the possibility that patients may have sought out or been provided information through social network activity. It seems logical that patients may request information from others in their personal, professional, and affinity-related networks, including those mediated through technology (that is, “social networks” such as Facebook, Instagram, Twitter, LinkedIn, and so on). In these interactions, patients may receive information, support, or referrals from a combination of health care providers, separately knowledgeable others, or those without claims to specific knowledge. Items assessing reported levels of information acquired through these reciprocal interactions could logically then load with a number of factors observed in this data set, depending

on patients’ other information acquisition behavior. For example, if the venue for using social media to seek out information is the primary behavioral driver for doing so, and patients who use social media are also likely to look up information through other Web-based resources, such items would be likely to load with the online patient information factor. If social media simply act as a means of accessing geographically dispersed friends and acquaintances for the purpose of information gathering, they may load (and possibly strengthen the reliability of) the conversations with non-health care providers factor eliminated during the described item analysis. Identification of other such venues of information will be critical to further refining and improving the viability of the informational media questionnaire for future research.

CONCLUSION

Any social-ecological conceptualization of how best to inform and support medical patients, including those being treated (or deciding whether or not to be treated) with complex technological therapies, relies on a distinct understanding of how patients learn about medical diseases and treatments. In this article, we proposed a preliminary version of a measure meant to quantify the health information acquisition activity reported by patients with ICDs. Four factors comprising nine total items were identified and retained for use in future research, but additional effort is needed to further refine these items, increase their reliability and psychometric stability, and improve their applicability to other treatment processes. We hope that the items and factors defined herein can serve as a scaffold in future medical social work research, aiding in the development of improved social work interventions for patients at risk of QoL or other problems related to these therapies. **HSW**

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