

Moral Distress Among Consumer Health Information Professionals: An Exploratory Study

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Résumé de l'article

Objectives – In recent years, moral distress has become a topic of interest among health professionals. Moral distress is most commonly described in the nursing literature, and refers to a situation wherein an individual knows the correct action to take, but is constrained from doing so. While moral distress differs from the classic ethical dilemma, in recent years practitioners and theorists have advocated for a broadening of the definition of moral distress. To date, no study has examined another group of individuals who frequently interact with patients and who may be constrained by the confines of their role - Consumer Health Information Professionals (CHIPS). The objective of this study was to determine if CHIPS experience moral distress and/or ethical dilemmas, and to determine what, if any, coping strategies these individuals have developed.

Methods – This study employed a mixed methods approach. Quantitative data were gathered via an online survey which was distributed to relevant consumer health information professional electronic mail lists. The survey contained demographic questions and a series of questions related to potential discomfort within the context of work as a consumer health information professional. Qualitative data were also gathered through phone interviews with CHIPS. Interview questions included the participant's definition of moral distress, professional experiences with moral distress, and any coping strategies to manage said distress.

Results – The authors received 213 survey responses. To test whether any of our demographic variables help to explain survey response, we used STATA to calculate Pearson correlation coefficients. Individuals who were more likely to experience discomfort in their occupation as CHIPS included individuals with less experience and individuals who identified as Black and Latinx. Interview data indicated that participants most commonly experienced ethical dilemmas related to censorship, providing prognosis information, and feeling constrained by institutional policies. Few interview participants described scenarios that reflected moral distress.

Conclusions – CHIPS do not appear to experience moral distress, at least according to its most narrow definition. CHIPS do consistently experience distinct ethical dilemmas, and the most durable patterns of this phenomenon appear to be related to experience level and racial identity. In recent years, researchers have raised calls to broaden the definition of moral distress from its narrow focus on constraint to include uncertainty, and CHIPs do experience moral uncertainty in their work. Further study is needed to determine how to best address the impacts of discomfort caused by ethical dilemmas among these groups.

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Research Article

Moral Distress Among Consumer Health Information Professionals: An Exploratory Study

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Abstract

Objectives – In recent years, moral distress has become a topic of interest among health professionals. Moral distress is most commonly described in the nursing literature, and refers to a situation wherein an individual knows the correct action to take, but is constrained from doing so. While moral distress differs from the classic ethical dilemma, in recent years practitioners and theorists have advocated for a broadening of the definition of moral distress. To date, no study has examined another group of individuals who frequently interact with patients and who may be constrained by the confines of their role - Consumer Health Information Professionals (CHIPS). The objective of this study was to determine if CHIPS experience moral distress and/or ethical dilemmas, and to determine what, if any, coping strategies these individuals have developed.

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Introduction

Originally discussed in nursing literature, the concept of moral distress is evolving and has more recently been explored in various healthcare professions. In 1984, Andrew Jameton described moral distress as a phenomenon that arises “when one knows the right thing to do, but institutional constraints

make it nearly impossible to pursue the right course of action” (Jameton, 1984, p. 6). While Jameton and his contemporaries’ discourse focused on the experiences of nurses, researchers have become interested in exploring this concept outside of the nursing profession, as well as beyond situations involving an institutional constraint. Fourie (2015) sought to expand the definition of moral distress beyond

nurses and experiences of constraint, proposing that moral distress occurs when health professionals experience a psychological response due to a moral conflict, restraint, or uncertainty.

While this evolved definition allows us to explore the experiences of all healthcare workers, it is important to understand the difference between moral distress, moral conflict, and ethical dilemmas. Moral conflict occurs when “when duties and obligations of healthcare providers or general guiding ethical principles are unclear” (Jormsri, 2004, p. 217), while an ethical dilemma involves “the need to choose from among two or more morally acceptable options or between equally unacceptable courses of action, when one choice prevents selection of the other” (Ong et al., 2012, p. 11). Ethical dilemmas and moral conflicts are often closely related to the experience of moral distress in healthcare professionals. As these concepts are explored and refined, the authors of this study sought to understand the experience of Consumer Health Information Professionals (CHIPS). CHIPS are information professionals providing consumer health information, or health information to non-healthcare professionals, in a variety of settings (Reference and User Services Association, 2015). Working in public, hospital, and other specialized libraries, these professionals regularly interact with patients and families at distressing times. While there is a growing interest in moral and ethical issues within the Library and Information Sciences profession, information professionals who provide healthcare information to the public have not been the focus of a study on moral distress. These information professionals frequently interact with patients in a variety of settings, and may be constrained by their role, resources, or institution. Furthermore, one author personally experienced a feeling of constraint while assisting a patron with a consumer health information inquiry.

Literature Review

Beginning in the 1980’s, the majority of studies exploring moral distress consider the experiences of nurses. This continued focus is because Jameton’s formative definition of moral distress necessitates the existence of “institutional constraints” (1984, p. 6). Many researchers describe nurses as particularly prone to situations where they must carry out and often bear the consequences of others’ decisions (Marshall & Epstein, 2016). Similarly, the Moral Distress Scale, developed by Corley (1995), which measures nurses’ experiences of moral distress, focuses on various limitations of agency, such as “institutional constraint.” Exploring nurses’ experiences using the Moral Distress Scale as well as other measures, researchers have found that moral distress manifests in various forms of psychological distress as well as physical manifestations. In a recent review, Morley, Ives, and Bradbury-Jones (2019) report “sleeplessness, nausea, migraines, gastrointestinal upset, tearfulness and physical exhaustion” (p. 655) in nurses experiencing moral distress. This phenomenon also has a direct effect on patient care, as Oh and Gastmans’ (2015) report that nurses with a high level of moral distress experience depersonalization, where they emotionally distance themselves from patients. Finally, moral distress is a documented threat to the healthcare workforce itself, as Whitehead, Herbertson, Hamric, Epstein, and Fisher (2015) reported that “providers who had left or considered leaving a position in the past reported moral distress mean levels significantly higher than those who had never considered leaving” (p. 123). It is important to note that Whitehead et al.’s survey included all healthcare professionals in the authors’ healthcare system.

In recent years, researchers have studied moral distress in non-nursing healthcare professions, such as healthcare assistants (Rodger, Blackshaw, & Young, 2019), veterinarians

(Moses, Malowney, & Wesley Boyd, 2018), medical students (Camp & Sadler, 2019), physician trainees and residents (Dzeng et al., 2015; Sajjadi, Norena, Wong, & Dodek, 2016), and Oncologists (Hlubocky, Spence, McGinnis, Taylor, & Kamal, 2020). This research is happening in tandem with the evolution of Jameton's formative definition, as evidence of moral distress is becoming apparent across healthcare fields. Like many nursing researchers, Sajjadi et al. (2016) also report an increased likelihood to leave the job or profession in internal medicine residents experiencing high levels of moral distress. While we are beginning to appreciate the prevalence of moral distress among a variety of patient-facing healthcare workers, studies have not focused on the experiences of CHIPS.

At the time of this writing, Library and Information Science (LIS) literature has reported very little research on moral distress and moral conflict. Most research on the broader topic of the distinction between right and wrong within matters relating to the profession has focused primarily on ethical dilemmas. Despite the fact that research nearly 30 years ago explored "moral conflict" as experienced by librarians, recent scholarship has not expanded upon this topic much. This is particularly surprising within health and medical librarianship, as broader medical literature continues to assess related concepts of morality. This paper can help contribute to the development of a body of knowledge on morality within library and consumer health information literature.

In 1993 Broderick describes 19th century librarians as self-defined "moral arbiters" (p. 447) of society, responsible for determining appropriate and inappropriate information for their constituencies. Framed in the context of collection development, the central thesis of the piece is the obligation of public libraries to shirk the idea of a universal morality and acquire materials with myriad points of view on a subject. Low (2002) also examines moral conflicts within collection development,

specifically related to the tension film librarians can face when deciding between acquiring movies featuring a diverse array of perspectives and dominant preferences of the library's parent company. He argues that true morality cannot exist in a library collection "without recognizing all voices, i.e. without a balance of perspectives" (p. 40).

However, ethical dilemmas have been repeatedly addressed in various library settings, including hospital, academic, and public. Librarians experience ethical quandaries across departments and roles, including reference services (Luo & Trott, 2016), reader's advisory (Lawrence, 2020), the organization of information (McCourry, 2015), privacy/confidentiality (Elliott, 2015), and RFID technology (Thornley, Ferguson, Weckert, & Gibb, 2011). Some researchers are generating strategies for preparing people to resolve ethical dilemmas before they even complete their LIS graduate programs. Walther (2016) details the development of problem-based learning techniques to teach LIS graduate students critical skills for handling ethical dilemmas in their future careers. This pedagogy is framed in part by the definition of an ethical dilemma as occurring when "two or more moral obligations come into conflict" (Walther, p.181).

Murphy (2001) elucidates ethical dilemmas faced by hospital librarians, chiefly the pressure to choose between prioritizing the needs of their institution versus collective social welfare, or the mores of the broader library profession. The stakes are high here, as the actions of hospital librarians directly impact the physical and psychological well-being of patrons (patients and their loved ones). Rigorous training in and dissemination of the professional ethics of the field can help this disconnect. Professional codes, such as the Medical Library Association's Code of Ethics for Health Sciences Librarianship (last updated in 2010), can play an important role in individually or collaboratively working through job-related ethical dilemmas.

In 2014 Byrd, Devine, and Corcoran surveyed 500 MLA members and learned that while 80% of respondents knew of the Code, nearly one third were unaware when they last consulted it for guidance. While clearly an invaluable resource for information professionals, the Code's principles do not directly address morality within informed decision making. One participant of this study, when surveyed on key issues that the Code does not explicitly cover, responded that "honesty, fairness and morality" (p. 269) should be added as principles that librarians are professionally obligated to follow.

Aims

The impetus for this study was grounded first and foremost in a combination of shared professional and close personal connections with nurses, as well as professional experiences as information professionals. One author identified a feeling of moral distress caused by constraint in assisting a patron with a consumer health information inquiry, and began to construct a project to deeper examine these experiences. All three authors have encountered ethical dilemmas in the course of either providing consumer health information services or teaching research skills to nursing students.

Two research questions can be used to frame this study. First, do CHIPS experience moral distress or ethical dilemmas while performing their daily job duties? Secondly, if individuals experience moral distress or ethical dilemmas, what coping strategies, if any, have they developed?

Methods

The study employed a mixed methods approach. In April 2020, the study was determined to meet the regulatory exemption for IRB by Memorial Sloan Kettering Cancer Center's Human Research Protection Program under 45 CFT.101(d)(2).

Contemporary moral distress instruments (e.g., the Moral Distress Scale-Revised) are heavily focused on issues surrounding direct patient care, which may not be applicable to CHIPS. As a result, we developed an instrument using the secure web application REDCap.

The survey contained questions on basic demographic and occupational questions along with a series of questions designed to measure feelings of discomfort and distress within the context of consumer health information librarianship. To assess personal values, the survey also asked belief-oriented questions related to patient advocacy and empowerment. Non-demographic questions were posed on a Likert scale from 1-6 (1 = Strongly Disagree; 2 = Disagree; 3 = Mildly Disagree; 4 = Mildly Agree; 5 = Agree; 6 = Strongly Agree). The survey instrument has been included as Appendix A. The survey questions were primarily intended to measure CHIPS' experiences of ethical dilemmas. However, because of the somewhat ambiguous nature of moral/ethical phenomena, some of the survey questions could address both ethical dilemmas and moral distress, depending on how the respondent interpreted the question. For example, for question #3 ("I feel licensing agreements with vendors prohibit me from sharing information with patients in the way I would like") one could argue that a respondent who "agrees" or "strongly agrees" with this statement is experiencing moral distress because he/she/they feels that providing free and unencumbered access to information for all consumers is the morally correct course of action, and feels *constrained* by licensing agreements. This person may, on moral grounds, feel that all information should be free and that any barriers to openness are morally reprehensible. However, one could also argue that a respondent who "agrees" or "strongly agrees" is experiencing an ethical dilemma if they feel that both choices are *morally acceptable* and simply don't know which to choose. This respondent might respect the legality of restrictions to proprietary information and feel they have these restrictions have value,

but at the same time may wish their patrons could have free access.

The survey was disseminated in early May 2020 and remained open to responses until June 16, 2020. It was disseminated to 22 electronic mail lists geared towards medical, academic, and public library information professionals. No incentive was offered for completing the survey. STATA was used to complete statistical analysis. The raw survey data has been openly deposited.

Survey respondents had the option to include their contact information if they wished to participate in a follow-up interview. While the survey assessed if CHIPS were experiencing distress in general, the aim of the interviews was to determine if the distress CHIPS experience occurs within the context of moral distress or ethical dilemmas.

Interview questions were open ended and focused on three components: 1) the participant's understanding and personal definitions of moral distress, 2) the participant's experience with moral distress in the context of being a consumer health information professional, 3) any coping strategies the participant had developed to manage moral distress. Interviews continued until a saturation point in thematic information was reached, resulting in 14 total interviews. Due to time constraints, only one author coded the interviews. Interviews were manually coded in a Google sheet, resulting in 21 codes. Wherever possible, the author used rich or thick descriptions assessing the interview data, making the code descriptions as detailed as possible. Appendix B includes the interview schedule. The interview codebook has been openly deposited with the raw data.

Interviews were conducted by one author using Zoom. Prior to the interviews, participants received informed consent documentation. Phone interviews were recorded and transcribed using TapeACall Pro software. Zoom interviews were recorded and manually transcribed.

Interviews completed by phone were automatically transcribed using the TapeACall Pro transcription feature, but required some manual cleanup. Interviews took place in May 2020 and June 2020.

Survey Population and Demographics

Consumer health information (CHI) is defined as "information on health and medical topics provided in response to requests from the general public, including patients and their families. In addition to information on the symptoms, diagnosis and treatment of disease, CHI encompasses information on health promotion, preventive medicine, the determinants of health and accessing the health care system" (Reference and User Services Association, 2015). Any professional working in this role and self-identifying as a CHIP qualified to participate in this study.

The authors received 213 survey responses; Table 1 presents summary statistics of this sample. The majority of the respondents identified as female (81%); white (62%); had a MLS, MIS, or MLIS degree (66.2%); or had an MLS, MIS, or MLIS and another advanced degree (16.9%), bringing the total of respondents who had an MLS, MIS, or MLIS to 83%. Respondents were aged 41-60 (49%), and were not licensed as medical professionals (94%). Ten respondents preferred not to provide either racial identity (3.3%) or gender identity (1.4%) and were excluded from the regression analyses. Respondents were mainly employed by academic medical centers (43%), hospitals (28%), and public libraries (16%). The amount of experience among respondents was fairly evenly distributed, 8-20 years' experience was most frequently reported (30%), and over 20 years' experience the least frequently reported (21%).

In order to understand how our sample compared to the overall population, we examined data from a demographic survey of Medical Library Association members (Pionke, 2019). We found that compared to the

Table 1
Sample Characteristics

	N	%
Age		
Under 25	5	2.3%
25-30	16	7.5%
31-40	35	16.4%
41-50	50	23.5%
51-60	56	26.3%
61-70	40	18.8%
70+	11	5.2%
Gender Identity		
Female	173	81.2%
Male	33	15.5%
Gender non-binary	4	1.9%
Prefer not to say	3	1.4%
Racial Identity		
White/Caucasian	133	62.4%
African American/Black	24	11.3%

Hispanic/Latinx	24	11.3%
Asian American/Asian	12	5.6%
American Indian/Alaska Native	1	0.5%
Native Hawaiian/Pacific Islander	0	0.0%
Middle Eastern/North African	2	0.9%
Prefer not to respond	7	3.3%%
Other/not provided	10	4.7%
Educational Background		
Master of Library and Information Science/Master of Library Studies/Master of Information Studies	141	66.2%
MLS, MLIS, or MIS AND other advanced degree (i.e. other master's degree or doctoral degree)	36	16.9%
Advanced degree (i.e. other master's degree or doctoral degree), not MIS, MLIS, or MLS	18	8.4%
Other	11	5.2%
Undergraduate degree only	7	3.3%
Medical License		
Does not have a medical license	201	94.4%
Does have a medical license	12	5.6%

Years of Consumer Health Experience		
Less than 12 months	8	3.8%
1-4 years	39	18.3%
4-8 years	39	18.3%
8 years-15 years	53	24.9%
15 years-20 years	29	13.6%
20 years-25 years	22	10.3%
25 years-over 35 years	23	10.8%
Years in Current Position		
Less than 12 months	12	5.6%
1-4 years	60	28.2%
4-8 years	40	18.8%
8 years-15 years	43	20.2%
15 years-20 years	28	13.2%
20 years-25 years	15	7.0%
25 years-over 35 years	15	7.0%
Type of Institution Where Employed		
Private hospital	5	2.4%

Not-for-profit hospital	45	21.1%
Community hospital	6	2.8%
Academic medical center	48	22.5%
Academic library	39	18.3%
Community health center	0	0%
Government agency	17	8.0%
Public library	30	14.1%
Unemployed	1	0.47%
Other	22	10.3%

respondents in the MLA survey (n=918), our respondents identified as being less white (62% vs. 72%), slightly more female (81% vs. 79%), and were similar in age range. It should be noted, however, that only 1% of the respondents in the MLA study identified “consumer health” as their primary job function.

Results

Table 2 presents average Likert scores (1 = Strongly Disagree, 6 = Strongly Agree), standard deviations, and overall proportions of responses for questions relating to moral distress. High average Likert scores (5+) indicate that the majority of respondents overwhelmingly agreed or strongly agreed with a particular statement. For example, respondents expressed strong preferences for patient rights (90.6% agreed or strongly agreed that patients should have access to as much health information as they wish; 92.9% agreed/strongly agreed that health

professionals should take an active role in patient education and engagement). Similarly, these variables report small standard deviations (less than 1), indicating that the distribution of Likert scale responses is highly bunched.

Conversely, low average Likert scores (less than 3) were more common on questions which emphasized CHIP unpreparedness. Over half of the sample disagreed with the statements “I often feel unable to provide patients with the health information they are looking for” and “I often worry that I lack the necessary skills, education or knowledge.” However, standard deviations on these “disagree” statements were larger (1.4 and 1.5, respectively), indicating more variability in response.

While clear majorities emerged in response to certain issues, respondents were also divided around numerous issues. A fairly even split in agreement and disagreement can be seen in

Table 2
Likert Scores

Question	% Strongly Disagree	% Disagree	% Mildly Disagree	% Mildly Agree	% Agree	% Strongly Agree
"I often feel unable to provide patients with the health information they are looking for."	16.9% n=36	37.6% n=80	10.8% n=23	17.8% n=38	14.6% n=31	2.3% n=5
"I often worry that I lack the necessary skills, education, or knowledge to provide patients with the information they are looking for."	16.9% n=36	38% n=81	10.8% n=23	15% n=32	13.1% n=28	6.1% n=13
"I feel like licensing agreements with vendors prevent me from sharing information with patients in the way I would like."	16.0% n=34	26.3% n=56	8.0% n=17	15.5% n=33	24.4% n=52	9.9% n=21
"I often feel like patients confuse my role with their health care provider."	9.4% n=20	27.2% n=58	10.3% n=22	15.5% n=33	29.1% n=62	8.5% n=18
"I often feel like I do not have adequate time to spend on search requests for patients."	10.8% n=23	28.2% n=60	10.8% n=23	14.1% n=30	26.3% n=56	9.9% n=21
"I often feel pressured to provide prognosis information or survival rates for patients."	16.4% n=35	30% n=64	12.2% n=26	11.3% n=24	24.4% n=52	5.6% n=12
"I often feel patients expect me to provide them with positive information about their prognosis."	8.5% n=18	31.0% n=66	12.2% n=26	17.8% n=38	22.1% n=47	8.5% n=18
"I often feel I must inform patients the resources they have found on their own are not evidence based, credible or reliable."	3.8% n=8	11.3% n=24	6.1% n=13	17.8% n=38	41.3% n=88	19.7% n=42

"I often feel torn between the different constituencies (e.g. patients, administrators, clinicians) with whom I work."	7.5% n=16	33.3% n=71	9.9% n=21	16.9% n=36	22.5% n=48	9.9% n=21
"I feel frustrated with the many roles I am expected to perform."	7% n=15	25.4% n=54	7.5% n=16	16% n=34	29.1% n=62	15% n=32
"I often feel caught in the middle between trying to appease patients, caregivers, and their own health care providers."	11.7% n=25	17.8% n=38	12.2% n=26	16.4% n=35	33.3% n=71	8.5% n=18
"I am able to successfully cope with the challenges of my position."	2.3% n=5	11.3% n=24	5.6% n=12	16.4% n=35	54% n=115	10.3% n=22
"My library has an adequate budget."	8.9% n=19	26.8% n=57	8.9% n=19	14.1% n=30	33.3% n=71	8% n=17
"My library has adequate staff with expertise in providing consumer health information services."	8.4% n=18	28.2% n=60	10.3% n=22	20.2% n=43	28.2% n=60	4.7% n=10
"I am able to acquire the resources I need to meet the information needs of my users."	2.3% n=5	40.4% n=86	9.9% n=21	17.8% n=38	21.6% n=46	8% n=17
"I have been concerned for my physical or mental health during times of emergency (e.g., terrorist attacks, pandemics, natural disasters) at my library."	8.5% n=18	24.4% n=52	9.9% n=21	22.5% n=48	21.6% n=46	13.1% n=28
"The administration of my organization understands the value and importance of my library."	9.4% n=20	24.9% n=53	6.6% n=14	14.1% n=30	33.3% n=71	11.7% n=25
"I believe patients and caregivers should have access to as much health information as they wish."	0% n=0	1.9% n=4	2.3% n=5	5.2% n=11	33.8% n=72	56.8% n=121

"I believe patients and caregivers should be active advocates for their own health care."	0% n= 0	0% n= 0	1.4% n=3	5.2% n=11	33.3% n=71	60.1% n=128
"I believe health professionals should take an active role in patient education and engagement."	0% n=0	0.5% n=1	0.5% n=1	6.1% n= 13	32.9% n=70	60.1% n=128

response to the question regarding patients confusing the role of the information professional with the role of a health care provider and not having enough time to spend with patients. About a third of respondents said they did not feel pressured to provide prognosis information to patients, or provide them with positive information about their prognosis, but respondents were likely to feel that they often must inform patients that the information resources they have located on their own were not evidence based.

Similarly, responses related to institutional pressure were mixed. While almost a quarter of respondents agreed with the statement that licensing agreements prohibited sharing information with patients, more than one quarter disagreed with this statement. Even though one third of respondents did not feel torn between the different constituencies they worked with, nearly 44% reported feeling frustrated with the many roles they were expected to perform.

Regression Analysis

To test whether any of our demographic variables help to explain survey response, we used Stata 14 to calculate Pearson chi-squared tests of independence. Response patterns about patient access and advocacy were systematically different by racial identity in a statistically significant manner ($\chi^2=27.4$, $p=.007$ and $\chi^2=18.2$, $p=.033$). Similarly, men tended to disagree more with the idea that health professionals should

take a role in educating patients, and that they were being asked to provide prognosis information ($\chi^2=29.8$, $p=.000$ and $\chi^2=23.9$, $p=.008$). Figure 1 displays a spineplot for the results, by gender, for the question "I often feel pressured to provide prognosis information or survival rates for patients." Figure 2 presents the question results by racial identity. Spineplots were created in Stata, utilizing a software package designed by Cox (2008).

Those who worried about being unprepared were statistically more likely to be the young ($\chi^2=58.1$, $p=.000$, for the variable "unprepared," and $\chi^2=84.1$, $p=.000$ for the variable "imposter") and those in the field for shorter durations ($\chi^2=25$ $p=.049$ for the variable "unprepared" and $\chi^2=45.7$ $p=.000$ for the variable "imposter"). We also found that those who identify as Black or Latinx are more likely to feel frustrated with role confusion when it concerns their jobs as CHIPS ($\chi^2=54$, $p=.000$). These racial identity groups also report that they feel required to provide positive responses to patron inquiries, to provide prognosis information, and are more likely to fear for their safety while at work in statistically significant patterns ($\chi^2=84.1$, $p=.000$, $\chi^2=86.6$, $p=.000$, and $\chi^2=56.7$, $p=.000$).

Interview Data Characteristics

Fourteen interviews were conducted and interview participants were first asked to give their personal definition of moral distress. Some interviewees gave definitions that closely matched the "classic" definition of moral

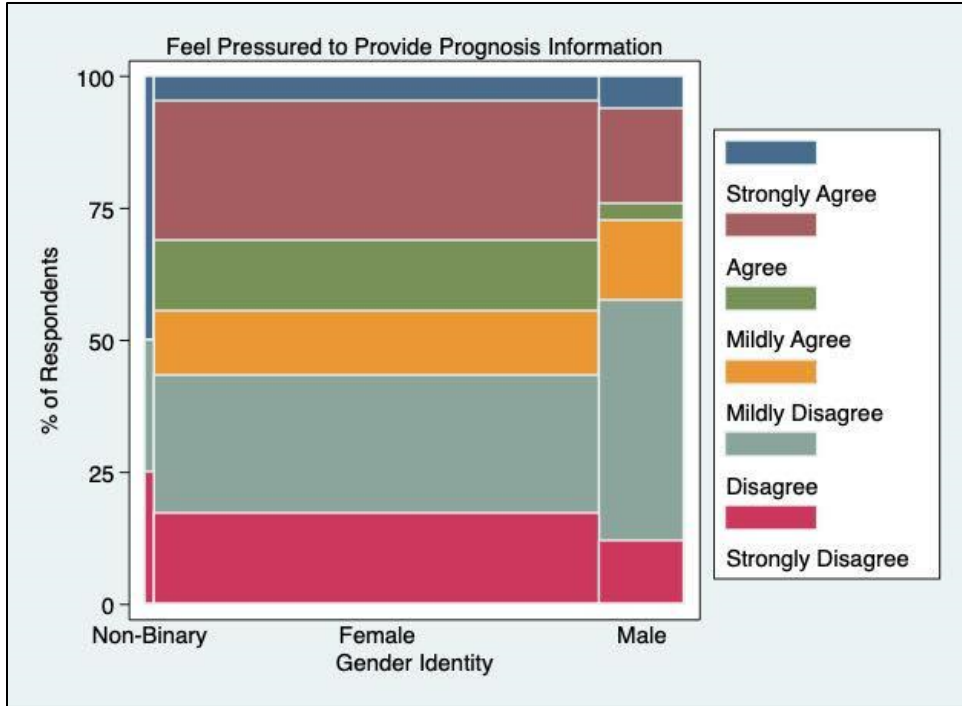


Figure 1
 Respondents' perceptions of providing prognosis information by gender.

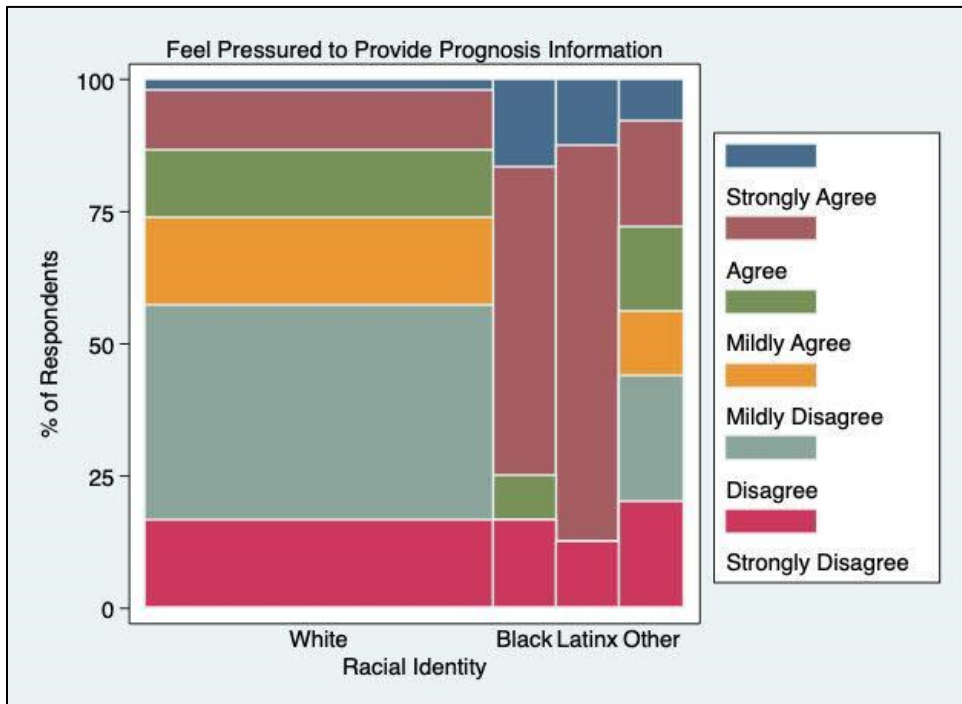


Figure 2
 Respondents' perceptions of providing prognosis information by racial identity.

distress, but more often their definitions were more closely aligned with a moral or ethical dilemma. Some interviewees were unable to provide a clear definition, but instead referred to a survey question that particularly resonated with them. This resulted in 4 original definitions provided during the 14 interviews.

The authors asked interview participants to identify how they experienced moral distress in their work as CHIPS, and several themes emerged. The first centered around role confusion, wherein consumers do not understand the purpose of the consumer health library or the role of the consumer health information professional, and do not recognize that the consumer health information professional is not a health professional. Respondents noted that this role confusion usually manifests in patrons seeking specific medical advice or recommendations from them, including dosing information for medications or interpreting medical test results.

Several interview participants reported feeling discomfort when having to inform patients that the information they have found on their own was not evidence based. In doing their own health information research, consumers may find health information and then desire “confirmation” from a consumer health information professional that the information they have found is in fact evidence based. Respondents report this is more common when patients are seeking alternative or integrative therapies in place of, rather than in complement to, traditional medicine. Another common source of internal conflict among the interview participants related to being asked to provide prognosis information including survival rates/outcomes:

“I have that mental list of diagnoses that I want people to not ask me. Because I know what the situation looks like, pancreatic cancer, for example. I hate it. Especially in a case like that, when survival rates aren’t good, but they don’t know that yet. So they are just looking at

treatment situations or whatever. And I never know how far to go. Like should I be offering them information on palliative care?”

Several interview participants raised the issue of providing “too much” information, particularly when assisting patients who were newly diagnosed with a condition that has particularly dire outcomes. Participants reported not wanting to “overwhelm” their patrons with information, but feeling that not providing them with the level of information requested would amount to censorship:

“I... worry about inadvertently being a censor, not providing them with enough information for them to make a health care decision because I know they’re not at a place where they can do that effectively.”

A lack of available information on a particular health topic was also often a source of discomfort for interview participants. In this instance, assisting individuals with rare diseases and conditions can be particularly challenging. Other participants reported frustration with being unable to find health information resources available in languages other than English.

Interview participants described several instances wherein they struggled with institutional policies to remain “neutral:”

“The Library can’t recommend one [health care] facility over another, even though I might know that one facility has a worse record on something. And that I struggle with, too, so I’m always saying get a second opinion, look at other places. Here are the statistics.”

One interview participant described a scenario wherein despite being hired as a “community health librarian,” she had been constrained by the administration of her institution from actively providing services to the local community and was instead relegated to providing services to a lower need community

that was directly affiliated with her institution (a university).

While not directly related to ethical constraints or dilemmas, interview participants reported several scenarios related to their work as CHIPS that caused them to feel a sense of generalized distress. Two interview participants felt they lacked the necessary training and skills to function competently in their positions and that they experienced feeling of inadequacy and stress. Finally, interview participants reported that simply being exposed to the stress of patients, caregivers, and family members can be upsetting, particularly if they have not received adequate training to cope with these types of stressors:

"They come in with a diagnosis, and I'll help them, it's not a good diagnosis, and they'll be upset. You're trying to help them, and they start crying. They're visibly upset, which makes me upset."

Interview participants identified several coping strategies for managing their experiences of moral distress, as well as emotional distress in the professional setting. Six interview participants reported relying on a network of professionals for additional support when the patron they were helping was in distress or if the patron asked for resources/information beyond the scope of the consumer health information professional's role. These professionals include social workers, patient advocates, volunteer services, patient educators, and dieticians. One respondent noted the benefits of support from health care providers:

"It's good to have nurse colleagues who can help me process things, and know how to deal with weird situations, like being pulled into people's medical and legal issues. As librarians we want to help, so it's helpful because they know where to refer people for things like living wills."

Participants reported strengthening their professional networks over time, as they became

more familiar with institutional resources and personnel. Several participants reported that they simply felt less distress as they gained familiarity with the types of encounters and requests that typically upset them, and as they became more comfortable with the demands of their role and their surroundings. Using a disclaimer (either verbally or in a written form such as a sign) which described the role of the consumer health information professional and its limitations was also reported.

Working to ensure patients are effective advocates for their own health was another coping strategy reported by participants. One subject described alleviating discomfort by encouraging the patients he worked with who were feeling overwhelmed by their diagnosis to write down specific questions they have for their health care provider and to practice asking them aloud. Other participants reported encouraging patients to bring research studies or consumer health information they had located to their health care provider. Other coping strategies were less frequently reported and included indulging in escapist entertainment, using reflective practice (e.g., journaling), using institutional staff assistance programs, and actively circumventing bureaucratic systems to aid their patrons.

Discussion

The study finds that CHIPS do experience generalized distress within their professional roles, and in some cases this distress appears to be directly related to the nature of their role. For example, one interview participant described her struggle with providing information on Morgellons Disease, a controversial condition which many health professionals describe as a form of delusional parasitosis, but has also been described by a smaller group of medical professionals as a legitimate dermatological condition. The controversial nature of the condition left this interview participant feeling torn between her patrons who were convinced they suffered from the condition and the lack of

evidence that the condition actually exists in the physical sense. CHIPS exist within a sort of interspace, with significantly more expertise of health information than the average consumer, but frequently without the licensure, education, and hands on knowledge of medical professionals. Navigating this interspace may prove challenging, particularly for individuals who are already faced with navigating organizational power structures and systemic pathologies (ex., racism, ageism).

Indeed, the distress experienced by consumer health professionals appears to be related at least in part to the level of support, or lack thereof, that they receive from their institution at large. While the majority of respondents felt they were able to successfully cope with the challenges of their positions (54%), one third reported that their library had an inadequate budget (33%), inadequate staffing to support consumer health information services (33%), and that the administration of their organization did not understand the value and importance of their library (33.3%). About a third (34.7%) of respondents also reported being concerned for their physical or mental health during times of an emergency.

While CHIPS appear to experience distress, it is beneficial to distinguish between distress that occurs in the course of one's occupation and distress caused by an *ethical dilemma* in a professional context. Again, an ethical dilemma is a situation in which two moral principles conflict with one another. Not all the scenarios described by the interview participants were true ethical dilemmas, but some were, including concerns about censorship, providing prognosis information, and feeling constrained by institutional policies. The latter phenomenon, a feeling of institutional constraint, is associated with moral distress, but our interview participants were more likely to experience scenarios with competing moral drawbacks, rather than one obvious morally superior option. The most durable patterns of these

experiences of ethical dilemmas appear to be related to experience level and racial identity.

CHIPS do not appear, though, to experience moral distress, at least according to its narrow definition (knowing the correct action to take, but being constrained from doing so by external forces). Why don't CHIPS experience moral distress? One reason may be that the key component of moral distress, as traditionally defined, of "constraint" is less likely to be present. It may be that case that the constraint CHIPS experience within the course of their profession is felt less acutely than frontline medical professionals, such as nurses, who are directly responsible for the health and safety of patients. It also appears that CHIPS may confuse moral distress and ethical dilemmas, or conflate the two.

If moral distress is defined more broadly, as suggested by Fourie (2015), one could argue that CHIPS do indeed experience a degree of moral distress. Fourie argues that we should recognize that "constraint is not a necessary condition of moral distress and that such distress can arise from morally troubling situations other than those of moral constraint" (p. 580) and that moral distress should be expanded to include experiences related to moral uncertainty.

Limitations

The authors acknowledge that the study is limited by several factors. First, because there was no validated instrument to measure moral distress and ethical dilemmas among consumer health professionals, we did not use a validated tool. In future research, a validated tool may aid in further distinguishing between the nuanced and complex experiences of moral distress and ethical dilemmas. The purposive sampling technique used (leveraging electronic mail lists of interest to CHIPS) to identify potential survey respondents may have resulted in a degree of selection bias. Finally, only one interviewer coded the interviews. Using two or more coders in future studies would reduce the potential for

bias when identifying interview themes, as long as proper interrater reliability protocols are implemented.

Further Research

While this study provides burgeoning insight into the exploration of moral distress among CHIPS, additional research is needed to validate and expand on these findings to draw broader conclusions.

First, it would be valuable for outside researchers to apply the survey instrument developed by the authors to their own samples. The instrument was used for the first time in the present study, and did not undergo validity or reliability calculations. This process would help to ensure the instrument is consistent across applications, measures what it intends to measure, and that results can be extrapolated to a broader population.

Next, the results of the survey indicated that participants who are Black or Latinx experience greater distress in the CHI profession than people of other racial identities. These statistics are concerning and need further investigation in efforts to identify and ameliorate any racism or microaggressions causing this distress. While there aren't similar studies within LIS scholarship to compare these findings Dyo, Kalowes, and Devries (2016) found that Hispanic nurses reported much higher rates of moral distress than other ethnic groups, "suggesting that culture and ethnicity may play a role in the perception and experience of moral distress" (p. 1). A pertinent solution identified within nursing literature to address this problem was to begin studying moral distress as experienced by non-Western nurses (Prompahakul & Epstein, 2020), a project that could easily be replicated with CHIPS or librarians.

Conclusions

This study examined how CHIPS experience moral distress, ethical dilemmas, and the use of coping strategies for managing the negative impacts of these phenomena. While the study finds that CHIPS do not appear to experience moral distress according to its narrow definition focused on constraint, study results indicate that CHIPS do experience ethical dilemmas in the course of their work. The most durable patterns of ethical distress experienced by CHIPS appear to be related to experience level and racial identity, with younger, Black, and Latinx CHIPS experiencing ethical dilemmas at higher rates. Further study is needed to determine why there is a statistically significant relationship between these groups and their experiences with ethical distress. The interview data further elucidates how CHIPS interpret the phenomenon of moral distress and how this term is sometimes confused with ethical dilemmas. This issue could be ameliorated by professional associations creating a module on integral ethical codes of their area of librarianship and encouraging libraries to include participation in the module in onboarding for new hires. Additionally, Library and Information Science graduate programs can build greater content on morals and professional ethics into their foundational courses. Finally, while the experiences of the study participants do not fit the classic definition of moral distress, which is characterized by the presence of constraint, they do align with a more broadly defined version of moral distress. This definition, as described by Fourie (2015) allows for the inclusion of the experience of uncertainty to co-exist with the experience of constraint in moral contexts.

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Author Contributions

Robin O'Hanlon: Methodology, Formal analysis, Data curation, Visualization, Writing – original draft (equal), Writing – review & editing (equal) **Katelyn Angell:** Methodology, Writing – original draft (equal), Writing – review & editing (equal) **Samantha Walsh:** Methodology, Writing – original draft (equal), Writing – review & editing (equal)

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Appendix A
Survey Instrument

How old are you?

Under 25
25-30
31-40
41-50
51-60
61-70
Over 70

What is your gender?

Female
Male
Gender non-binary
Prefer not to say

Which of these best describes your racial identity?

African American/Black
American Indian/Alaska Native
Asian American/Asian
Native Hawaiian/Pacific Islander
Hispanic/Latinx
Middle Eastern/North African
White/Caucasian
Other/Not Provided
Prefer not to respond

What is your educational background?

Master of Information Science
Master of Library and Information Science
Master of Library Science
Advanced degree (i.e., other masters degree or
doctoral degree), not MIS, MLIS, or MLS
MLS, MLIS, or MIS AND other advanced degree
(i.e., other masters degree or doctoral degree)
Undergraduate degree only
Other
If "Other," please describe.

Are you currently, or have you ever been, a licensed medical professional (e.g. Registered Nurse, Medical Doctor)?

Yes
No

If you are currently or have been licensed medical professional in the past, please describe:

Years of consumer health librarian experience/providing health information to the public:

Less than 12 months

1 year - 2 years

2 years - 4 years

4 years - 6 years

6 years - 8 years

8 years - 10 years

10 years - 12 years

12 years - 15 years

15 years - 20 years

20 years - 25 years

25 years - 35 years

Over 35 years

Years in current position:

Less than 12 months

1 year - 2 years

2 years - 4 years

4 years - 6 years

6 years - 8 years

8 years - 10 years

10 years - 12 years

12 years - 15 years

15 years - 20 years

20 years - 25 years

25 years - 35 years

Over 35 years

Type of institution where you are employed:

Private hospital

Not-for-profit hospital

Community hospital

Academic medical center

Academic library

Community health center

Government agency

Public library

Unemployed

Other

If "Other," please describe.

For the remaining questions, please select one of the following values that best describes how you feel about each statement below:

Strongly Disagree
Disagree
Mildly Disagree
Mildly Agree
Agree
Strongly Agree

- 1) I often feel unable to provide patients with the health information they are looking for.
- 2) I often worry that I lack the necessary skills, education, or knowledge to provide patients with the information they are looking for.
- 3) I feel licensing agreements with vendors prohibit me from sharing information with patients in the way I would like.
- 4) I often feel that patients confuse my role with their health care provider.
- 5) I often feel I do not have adequate time to spend on search requests for patients.
- 6) I often feel pressured to provide prognosis information or survival rates for patients.
- 7) I often feel patients expect me to provide them with positive information about their prognosis.
- 8) I often feel I must inform patients the resources they have found on their own are not evidence based, credible, or reliable.
- 9) I often feel torn between the different constituencies (e.g. patients, administrators, clinicians) with whom I work.
- 10) I feel frustrated with the many roles I am expected to perform.
- 11) I often feel caught in the middle between trying to appease patients, caregivers, and their health care providers.
- 12) I am able to successfully cope with the challenges of my position.
- 13) My library has an adequate budget.
- 14) My library has adequate staff with expertise in providing consumer health information services.
- 15) I am able to acquire the resources I need to meet the information needs of my users.
- 16) I have been concerned for my physical or mental health during times of emergency (e.g. terrorist attacks, pandemics, natural disasters) at my library.
- 17) The administration of my organization understands the value and importance of my library.
- 18) I believe patients and caregivers should have access to as much health information as they wish.
- 19) I believe patients and caregivers should be active advocates for their own health care.
- 20) I believe health professionals should take an active role in patient education and engagement.

Contact information (Optional)

If you are willing to participate in a phone interview about moral distress and consumer health librarianship, please include your contact information (name and email address). Any information professional who provides health information to the public can participate. If you decide to participate in a phone interview, your information will be anonymous in the final publication.

Please ONLY include your contact information if you are interested in participating in a phone interview. If you are not interested in participating in a phone interview, leave this section blank.

Appendix B

Interview Schedule

1. Can you define “moral distress”?
2. a) Do you feel you have ever experienced moral distress in your role as a consumer health librarian (or as an information professional who provides health information to the public)?
b) If yes, in what ways have you experienced moral distress in your role as a consumer health librarian (or as an information professional who provides health information to the public)?
c) If yes, how has your experience of moral distress affected your ability to function in your job and your attitude toward your job?
3. a) If you have experienced moral distress in the course of your profession, what factors have contributed to your distress (e.g., number of years of experience, type of patient)?
b) If you have not experienced moral distress in your profession, how do you feel you have avoided this phenomenon?
4. a) If you have experienced moral distress in the course of your profession, have you employed to lessen your experience of moral distress?
b) If you have employed coping strategies, which strategies did you find the most effective and why?