Chapter #24

IMPROVING THE HEALTH BEHAVIOURS OF COPD PATIENTS: IS HEALTH LITERACY THE ANSWER?

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ABSTRACT
Chronic Obstructive Pulmonary Disease (COPD) is a leading cause of morbidity and mortality (Vogelmeier et al., 2017). Adherence to prescribed medications and adequate medication inhalation technique (MIT) is critical for optimal management of COPD, as is the proper use of the medication delivery device. O'Conor et al. (2019) found that lower health literacy (HL) was associated with both poor medication adherence and MIT. HL, according to the Process-Knowledge Model, consists of both processing capacity and knowledge (Chin et al., 2017). COPD most commonly occurs in older adults (Cazzola, Donner, & Hanania, 2007). Older adults tend to have lower processing capacity (Chin et al., 2017). The purpose of this study was to determine if HL was associated with medication refill adherence (MRA) and/or MIT. Fifty-seven participants completed a questionnaire package that included demographic questions, measures of HL, and assessments of MRA and MIT. A subset of twenty patients participated in qualitative interviews. Results indicated that lower HL was associated with both lower MRA and poor MIT, and qualitative findings revealed the need for further information. Future research should focus on testing educational materials that have been designed and/or reformatted to meet the lower processing capacity of older adults.

Keywords: chronic obstructive pulmonary disease, medication adherence, health literacy, health behaviours, cognition, older adults.

1. INTRODUCTION

COPD is a globally prevalent chronic disease that results in an obstruction in airflow from the lungs and varying respiratory symptoms (Vogelmeier et al., 2017). COPD is a leading cause of morbidity and mortality globally and contributes to substantial social and economic burden (WHO, 2011). Both medication adherence and adequate inhalation technique are essential for controlling symptoms and slowing COPD disease progression (Melani et al., 2011; Rodríguez-Rosin, 2005). Nevertheless, rates of medication adherence and adequate inhalation technique remain low (see Restrepo et al., 2008). Literature reviews have found that low medication adherence and poor inhalation technique are associated with a lack of understanding of the disease and its treatment (e.g., Blackstock, ZuWallack, Nici, & Lareau, 2016; Bryant et al., 2013). Very few studies, however, have examined the association of medication adherence and inhalation technique with health literacy. The purpose of the current research was to determine if health literacy was related to medication adherence and/or inhalation technique in a sample of older adults and to propose next steps for targeted educational materials and interventions.

2. BACKGROUND

Health literacy can be defined as "the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course" (Rootman & Gordon-El-Bihbety, 2008, p.11). It is estimated that 55% of Canadians aged 16 to 65 have low health literacy, with approximately 88% of individuals over the age of 65 having low health literacy (Rootman & Gordon-El-Bihbety, 2008). Concerning COPD specifically, Omachi, Sarkar, Yelin, Blanc, & Katz (2013) collected data on a cohort of 277 individuals, including measures of health literacy, health status, quality of life, and healthcare utilization. Even after controlling for sociodemographic factors, Omachi et al. (2013) found that lower levels of health literacy were associated with higher levels of healthcare utilization due to a worsening of symptoms. They postulated that higher healthcare utilization among participants with lower health literacy may be due to a lack of confidence in self-management skills, and they suggest that improving self-management skills may reduce healthcare utilization.

Two important health behaviours concerning the self-management of COPD are medication adherence and inhalation technique. Medication adherence refers to the patients' use of medication as it is prescribed (Bryant et al., 2013). Patients that use their medication more than the recommendations of the prescriber request refills sooner than expected and patients who underuse their medication request refills later than expected. Neither of these situations is optimal, and both are considered non-adherence. Medication inhalation technique refers to the technique used to inhale medication (Melani et al., 2011). Incorrect technique prevents patients from receiving the dosage of medication that is prescribed. Bryant et al. (2013) reported that rates of non-adherence to COPD medication were between 41.3% and 57% and that 31% exhibited incorrect inhalation technique.

Medication adherence and inhalation technique are critical for optimal disease management and prevention of exacerbations (Global Initiative for Chronic Obstructive Lung Disease, 2018). O'Conor et al. (2019) conducted an observational cohort study to determine if health literacy (i.e., Short Test of Functional Health Literacy in Adults) and cognitive abilities (i.e., global, fluid or crystallized) predicted medication adherence and inhalation technique of COPD patients living in the United States. These researchers found that both health literacy and certain cognitive abilities predicted medication adherence and inhalation technique. For example, they found that deficits in fluid cognitive abilities (e.g., processing capacity), but not crystallized cognitive abilities (e.g., knowledge), were associated with lower levels of medication adherence and poorer inhalation technique. Fluid cognitive abilities, but not crystallized verbal abilities, decrease across the life cycle (Park et al., 2002); thus, making this an important consideration when working with older adults as discussed in further detail below. Though their results could not be generalizable to non-urban areas, they suggest that both health literacy and lower processing capacity should be taken into consideration when caring for patients with COPD.

Processing capacity and health literacy are not unrelated. According to the Process-Knowledge Model, both processing capacity and knowledge are components of health literacy (Chin et al., 2017). Knowledge about a disease and the respective treatment is essential, but the effective delivery of knowledge may be hindered if a patient has lower processing capacity (e.g., working memory and processing speed). According to Chin et al. (2017), knowledge and processing capacity have two different age-related trajectories with processing capacity declining with age and knowledge remaining constant or increasing with age. COPD is primarily a disease of older adults (Cazzola, Donner, & Hanania, 2007). Therefore, understanding the role of health literacy in older adults and its association with the health behaviours of patients with COPD is important for reducing symptom exacerbation as well as healthcare utilization.

3. PRESENT STUDY

O'Conor et al.'s (2019) study examined the relationship between health literacy, medication adherence, and inhalation technique in a sample of older adults in a large urban center in the United States. The primary objective of the present study was to determine whether health literacy was associated with the specific health behaviours related to the control and the management of COPD in a sample of older adults across a predominantly rural province in Canada. It was hypothesized that, in this sample of older adults, lower levels of health literacy would be associated with lower levels of medication adherence and inhalation technique. A secondary objective was to examine participants' lived experience of COPD medication adherence and management, in order to inform the quantitative findings.

4. METHODS

4.1. Participants

See Table 1 for a description of all study participants compared to the qualitative interview subsample. Participants' ages ranged from 55 to 94 years.

4.2. Measures

4.2.1. Participant demographics

Participants completed a nine-item questionnaire that included questions regarding age, gender, income, marital status, living arrangement, employment, education, years using a primary inhaler, and smoking history.

4.2.2. Rapid Assessment of Literacy in Medicine (REALM; Davis et al., 1993)

The REALM was used to determine the participants' ability to *read* health terms. The REALM is a 66-item health-related word recognition test where the words are arranged in order of easy (i.e., fat) to increasing difficulty (i.e., Osteoporosis). For this research, the REALM was collapsed into two categories: inadequate ($\leq 6^{th}$ grade) and adequate ($\geq 9^{th}$ grade). The REALM had good internal reliability (α = .98).

4.2.3. Test of Functional Health Literacy in Adults (TOFHLA; Baker et al., 1999)

The full-length version of the TOFHLA was used to measure the participant's ability to *understand* health information. The TOFHLA consisted of a two-part assessment; part one provided the participant with medical information or instructions from which they answered questions to test their understanding of the information, and part two required participants to read text about medical topics and fill in the blanks of the text from a list of potential choices. For this research, TOFHLA had two categories: inadequate (0-74) and adequate (75-100). The TOFHLA had good internal reliability (α = .81).

Table 1.
Descriptive Statistics for All Participants Compared to Interview Subsample.

Variable	**All** (*n* = 57)	**Interview** (*n* = 20)
Age, M(SD)	70.84 (9.51)	67.7 (7.02)
Gender, %		
Male	36.8	35.0
Female	63.2	65.0
Education, %		
< Grade 8	24.5	5.0
< High school	21.1	20.0
High school	42.1	60.0
College/University	12.3	15.0
Current Smoker, %		
Yes	33.3	25.0
TOFHLA[a], %		
Inadequate	38.6	35.0
Adequate	56.1	65.0
REALM[b], %		
Inadequate	38.6	25.0
Adequate	59.6	75.0
MRA[c], %		
Sub-Optimal	40.4	40.0
Optimal	56.1	60.0
MIT[d], %		
Poor Technique	10.5	5.0
Good Technique	82.5	95.0

[a] TOFHLA = Test of Health Literacy in Adults; [b] REALM = Rapid Estimate of Adult Literacy in Medicine; [c]MRA = Medication Refill Adherence; [d] MIT = Inhalation Technique. Note: The discrepancies in totals reflect missing values.

4.2.4. COPD medication refill adherence (MRA)

Information regarding the participant's primary inhaler was gathered from pharmacy records. Participants were classified (see Hess, Raebel, Conner, & Malone, 2006) as having either optimal MRA (≥ 80) or sub-optimal MRA (< 80). For participants who were prescribed more than one medication for COPD, the MRA score was calculated for their primary inhaler.

4.2.5. COPD medication inhalation technique (MIT)

Inhalation technique checklists were used to assess MIT for individuals who were using either a metered-dose inhaler (MDI) or the HandiHaler (HH). As different steps are required for each device, different checklists were used to score inhalation technique depending on the type of device that they were using. Each checklist contained five critical errors. Participants were determined to have poor technique if they did not perform all of the essential steps correctly and good technique if they performed all of the essential steps correctly. These checklists were based on arbitrary criteria related to the proper technique of using an inhalation device and were developed by Melani et al. (2011). The initial Intraclass Correlation Coefficient of the first 30 inhalation technique videos did not meet the minimum criteria of .7. Raters met to discuss areas of disagreement and completed the remaining videos. The final inter-rater reliability was 1.0.

4.3. Procedure

Ethics approval was obtained by the Horizon Research Ethics Board before recruitment. Participants were recruited by 1) using pharmacy patient records from New Brunswick pharmacy databases; and, 2) recruiting participants themselves directly to the study by advertising the study online, in newspapers, on the radio, and other public places (e.g., COPD support groups). Patients were invited to participate in the study by the pharmacist and/or pharmacist-assistant if they were at least 40 years of age, had a smoking history, a self-reported diagnosis of COPD, and a targeted inhaler scheduled for daily use for at least one year. Only participants who had been prescribed a MDI or a HH were included in the study. Participants were excluded from participation if they had: an asthma diagnosis; been enrolled in a formal disease self-management program; refilled their medication(s) at more than one pharmacy within the past year; or, if they had three or more of the targeted inhalers for scheduled daily use. Once permission to contact and eligibility were established, a research assistant collected the measures and inhalation technique video from participants at their homes. All patients who agreed to participate were included in the study.

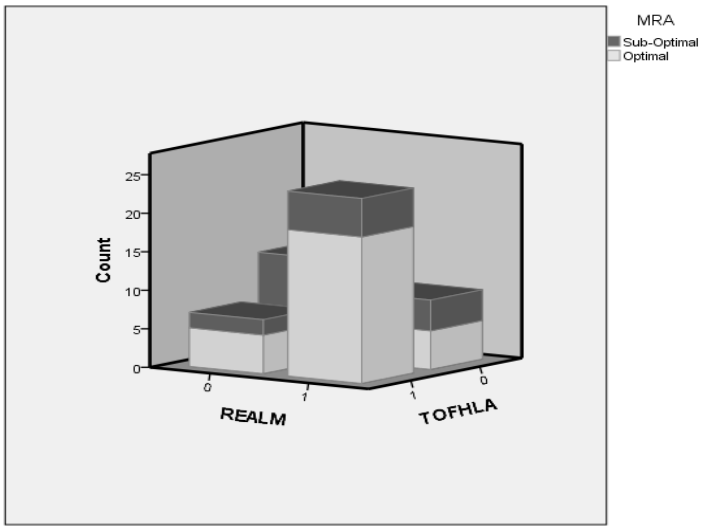
Finally, qualitative semi-structured interviews were conducted with a self-identified subsample of 20 participants. All those participants that consented (at the time of the initial questionnaire) to being contacted for an interview were then telephoned by research team members for further oral consent, upon review of the consent form (emailed or mailed to participants). Research team members conducted interviews over the telephone, which were digitally recorded. The interview questions pertained to their experiences of having COPD, adhering to medication, and what could facilitate adherence. The interview guide was piloted with two participants and, the questions were adjusted to gain as much information as possible, with possible lower literacy levels taken into account. The interviews were transcribed verbatim and uploaded to NVivo. Iterative thematic analysis (Braun & Clarke, 2006) was conducted on the qualitative data by three members of the research team (NH, LS, EK). Consensus of themes was reached between team members.

5. RESULTS

5.1. Quantitative

Two 2 x 2 chi-squares were used to analyze the relationship between health literacy and MRA. There was a significant association between health literacy, as measured by TOFHLA and REALM, and MRA (see Figure 1 and Table 2). The odds of adequate REALM was 4.67 (95% CI = 1.47, 14.86) times higher for the group with optimal MRA. Similarly, the odds of adequate TOFHLA was 7.35 (95% CI = 2.15, 25.14) times higher in the optimal MRA group.

Figure 1.
Bar Graph of REALM and TOFHLA by MRA.



Two additional 2 x 2 chi-squares were conducted to analyze the relationship between health literacy and MIT. There was a significant association between health literacy, as measured by TOFHLA and REALM, and MIT (see Table 2). The odds ratios for MIT and health literacy could not be calculated given that none of the COPD participants with adequate health literacy had poor MIT. In both chi-squares, 50% of the cells had expected values < 5. Even though Fisher's exact test was used, the result for MIT must be interpreted with caution. It should also be noted that, because four tests were conducted, a Bonferroni correction was applied and the significance level was set to .0125.

Table 2.
Results of Chi-Square Tests for Healthy Literacy, Medication Adherence, and Inhalation Technique.

		TOFHLA[a]				**REALM[b]**		
		Cramer's V	**OR**	**CI**	***X²***	**Cramer's V**	**OR**	**CI**
MRA[c]	11.02***	.46			7.17**	.36		
Sub-Optimal			3.02	1.48-6.15			2.33	1.23-4.43
Optimal			.41	0.22-0.78			.50	0.28-0.90
MIT[d]	7.07[e]	.38			9.25[f]	.42		
Poor								
Good			.77	0.62-0.97			.73	0.56-0.94

[a] TOFHLA= Test of Health Literacy in Adults; [b] REALM = Rapid Estimate of Adult Literacy in Medicine; [c] MRA = Medication Refill Adherence; [d]MIT = Inhalation Technique; [e]Fisher's Exact Test, p = .012 ; [f]Fisher's Exact Test, p=.004; *p<.05; **p<.01; ***.001

5.2. Qualitative

Iterative thematic analysis resulted in six themes emerging from the semi-structured interview data: *continuity of care*; *importance of pharmacy for information and care; medication self-management; "there needs to be more information"; drug costs a concern;* and, *"it's a lonely battle."* (Please note that the full qualitative study will be published at a later date).

Within the theme of *continuity of care,* participants discussed inconsistencies across the trajectory of care for their COPD, leading to the need to act as self-advocates for their healthcare and a lack of preventative care. However, within the theme *importance of pharmacy for information and care* community pharmacists were found to be important to participants in supporting their management of COPD. The theme *medication self-management* contained the explication by participants of their experiences managing COPD medications and the strategies they use to do so. Participants also discussed: the emotional social tolls of living with COPD, in the theme "*It's a lonely battle";* and, concerns about the cost of COPD medication, in the theme *drug costs a concern.*

One of the themes directly related to health literacy and the formulation of educational materials was *"there needs to be more information"*. In this theme many participants (12/20) expressed that they desired more information, including at the time of diagnosis, about the disease itself, how they can impact disease progression, how to get help when needed, and the supports available. Regarding what they perceived to be the overall need for more information, one participant stated, "*my big concern is on the COPD end of it is the lack of information that's available to anybody that has the particular problem"(P29).* When asked what information they were provided with upon diagnosis one participant stated, *"Um, really nothin'. They just come in and told me I had COPD and gave these puffers and, that was it." (P42)*. There were also participants who specifically wanted to know what to expect as their disease progressed, *"You know, what… what signs there is, like, when um, when I'm talking a lot you might notice my voice gets different and I think that must be from the COPD?...I don't know if it is, but if it is, people, they should tell you what, what to expect."(P4).*

6. DISCUSSION

In our study of 57 older adults, we found that health literacy was associated with health behaviours that are important to the management of COPD. More specifically, we found that lower levels of health literacy were associated with lower levels of MRA and MIT. We also determined that one of the themes of our qualitative study directly related to issues surrounding health literacy, supporting the quantitative results. More specifically, "*there needs to be more information*" not only reflected that the majority of participants expressed the need for a variety of information about COPD, but also that the information be provided throughout the progression of their chronic illness.

Our research supports and extends the findings of O'Conor et al. (2019). First, O'Conor et al. used the short version of the TOFHLA (s-TOFHLA) to measure health literacy, but we used both the TOFHLA (the full-length version) and REALM. Both measures of health literacy were significantly associated with COPD health behaviours. Second, O'Conor et al.'s sample consisted of patients located in two major cities in the United States. Our sample, though small, consisted of patients in a relatively rural area in Canada. Therefore, although O'Conor et al.'s study was limited by the lack of a non-urban sample, our research used a relatively non-urban sample, and our results supported the generalizability of their findings. Also, our research is novel in that it included the results

of qualitative interviews examining the lived experiences of patients with COPD. To our knowledge, no previous study has examined health literacy, MRA, and MIT using mixed methods.

Our research also supports a focus on the specific needs of older adults as it pertains to health literacy and the management of health behaviours. Patients with COPD tend to be older adults. Older adults are more likely to have lower levels of health literacy, and patients with lower levels of health literacy are more likely to have lower levels of MRA and poorer MIT. This is in turn associated with uncontrolled COPD symptoms and advancing disease progression (Melani et al., 2011; Rodríguez-Rosin, 2005). Further, one of the themes that emerged from the qualitative interviews was the need for more information about the prognosis, management, and treatment of COPD. Providing such information on COPD repeatedly and over the progression of the disease would address the informational needs of COPD patients as identified by our sample. Though increasing knowledge will help improve health literacy, it is only one part of health literacy.

According to the Process-Knowledge Model of health literacy and the findings of O'Conor et al.'s research, processing capacity also needs to be considered. Indeed, it may be crucial when the primary age group of the disease is older adults. Older adults are most likely to be affected by a decline in cognitive abilities such as processing speed (e.g., O'Conor et al., 2019). Therefore, the information that is provided to older adults needs to be tailored to meet their needs. In other words, information on COPD needs to improve not only in quantity but also in quality.

O'Conor et al. (2019) offered some suggestions. They noted that COPD educational materials may be improved by designing materials for the low reading grade level and providing concrete instructions (p. 24). They also noted that multi-step behaviours, like MIT, should be 'chunked' to enhance memory (e.g., "Ready, Set, Go!", p. 24). Chin et al. (2017) noted that materials should signal key concepts and present the information in a way that reduces the demands on processing skills such as search and reorganization. The use of timeline icons is another method suggested to reduce cognitive demand. In a series of experiments, Morrow, Hier, Menard and Leirer (1998) found that the use of timeline icons improved medication adherence.

Designers of COPD educational materials may consider the importance of information delivered via the internet. Morrow and colleagues (e.g., 2016, 2017) offered many important insights into how to effectively deliver electronic health information to older adults with low health literacy. In their review, Azevedo and Morrow (2018) note that presenting electronic information in icon (e.g., picture) format reduces cognitive load and improves memory. They suggest that icons for emotion improve comprehension given that it provides a means to evaluate without the need for an extensive written explanation. Finally, Azevedo and Morrow (2018) propose that presenting educational information in video-enhanced formats provides both verbal and non-verbal cues as well as face-to-face communication.

6.1. Study limitations

The major limitation of this study is the small sample size. Despite all of our attempts, only 57 patients with COPD agreed to participate. Another limitation was the initial issues with MIT coding. However, these issues were resolved between two experienced hospital pharmacists. Finally, though the qualitative study presented here is minimal, it does describe the results that are relevant to the quantitative study. The entire qualitative study is, as a whole, beyond the scope of the current study and is currently being reviewed for publication.

7. FUTURE RESEARCH

Though this research is limited by the sample size and initial issues with MIT coding, other researchers (e.g., O'Conor et al., 2019) have reported similar results. Future research should replicate this study with a larger sample size and consider the specific needs of older adults in regard to health literacy, medication adherence and inhalation technique. Specifically, designing and/or re-formatting and testing COPD patient materials with a focus on the specific needs of older adults with COPD should be considered. Materials that reduce cognitive demand by providing visual messages alongside simple wording, grouping material into chunks, and providing repeated messages should be considered. The most efficacious method may be an action-oriented research project where pharmacists, cognitive psychologists, and COPD patients collaborate to design needed educational materials and interventions.

8. CONCLUSION

Quantitative findings indicated that HL was associated with both lower MRA and poor MIT among older Canadian adults living with COPD. Participants in the qualitative sub-study reported unmet informational needs concerning COPD. A holistic and individualized approach to education and interventional efforts, encompassing both health literacy and appropriateness for older adults, is needed.

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