Discharge Instruction/Education Materials for Venous Thromboembolism (VTE): A Comprehensive Approach to Medication Management

Executive Summary

The Joint Commission
Department of Health Services Research
Background
It is widely acknowledged that patients discharged with venous thromboembolism (VTE) need to receive comprehensive discharge instructions so that they can manage their condition and its treatment in a way that is both safe and effective.¹⁻³ Discharge instructions for VTE have typically included medication management recommendations related to the use of warfarin.¹⁻⁴ In recent years, however, a growing number of alternatives to warfarin have become available and little was known related to if or how patient education and discharge instruction materials had kept pace with changing medication practices. Warfarin alternatives, like direct oral anticoagulants (DOACs), eliminated many of the complex monitoring challenges associated with warfarin, but patients discharged on DOACs and other anticoagulants still need appropriate discharge instructions to ensure the safe use of these medications. To learn more about the provision of patient education and discharge instructions for patients discharged on DOACs and other alternatives to warfarin, The Joint Commission Department of Health Services Research, with funding from Bristol Myers-Squibb / Pfizer, Inc., embarked on an 18-month project titled, Discharge Instructions for Venous Thromboembolism (VTE): A Comprehensive Approach to Medication Management.

Project overview
The project began in September of 2015 with an environmental scan to determine what information was available regarding the role of education and the provision of discharge instructions for VTE patients being discharged on anticoagulant medications other than warfarin. Upon the completion of the environmental scan, The Joint Commission issued a National Call for Examples to seek information regarding VTE patient discharge instructions and education currently being used by hospitals, stakeholders, relevant professional associations, and advocacy groups. Information was gathered through an electronic questionnaire, as well as through the voluntary submission of educational materials and examples of discharge instructions.

Project activities were guided by an eight-member Technical Advisory Panel (TAP) (see TAP member listing in Appendix A). The TAP provided subject matter expertise on anticoagulation therapy for VTE patients, strategic direction for project activities, as well as review of materials.

Project Findings
Environmental Scan
Articles and sources for the environmental scan were gathered through a comprehensive search of the medical and social science databases, including PubMed, PsycINFO, and CINAHL. Hand-pulled articles and grey literature were also reviewed. After identifying nearly 500 articles, only 37 articles (6%) met the initial inclusion criteria. These articles were then reviewed based on the following categories:

- **Need / gap.** Literature that identified or discussed a need for more patient education and / or a gap in patient knowledge regarding management, treatment, or safety concerns in using DOACs (n=24).
- **Adherence.** Literature that discussed the relationship of patient education or discharge instructions with adherence or compliance with anticoagulation therapy or treatment (n=14).
• **Impact / value.** Literature that discussed the impact or value of providing patient education or discharge instructions on measurable outcomes (n=10).

There was much overlap in the categorization of the articles, with many articles falling into more than one category. In addition to the categories above, an emergent theme was identified. Almost all the reviewed articles either identified, discussed, or recommended specific components that should be included in patient education or discharge instructions for patients on anticoagulants. These recommendations were later consolidated and used to evaluate the information provided through the questionnaire and the National Call for Examples. Overall, the environmental scan pointed to a lack of information regarding patient education and discharge instructions specific to DOACs, and it led the project team to proceed with the second phase of the project – the questionnaire and the National Call for Examples.

**Questionnaire**
Project staff developed an electronic questionnaire to solicit information regarding patient education or discharge instructions for VTE patients discharge on anticoagulants.

One hundred and four responses to the electronic survey were submitted and reviewed by the project team. Ninety-three (94%) respondents indicated that their organization provides discharge instructions and / or education materials for VTE (pulmonary embolism (PE) and / or deep vein thrombosis (DVT)) patients being discharged on anticoagulation therapy.

Organizations were asked to indicate if they provide discharge instructions and / or education materials for anticoagulation therapy, and if so, for which anticoagulant (DOACs, warfarin, unfractionated heparin, low-molecular-weight heparin (LMWH), and / or other anticoagulation therapies). The results indicated that organizations provide more patient discharge instructions and / or education materials for warfarin (n=89) than any of the other anticoagulants. Sixty-one respondents provide discharge instructions and / or education materials for DOACs, 33 provide discharge instructions and / or education materials for unfractionated heparin, and 63 provide discharge instructions and / or education materials for LMWH.

Organizations were also asked how they develop or obtain discharge instructions and educational materials, whether they were targeted to specific patient needs (limited English proficiency, health literacy) or other indicators, and whether they evaluated their materials. More respondents indicated they developed discharge instructions / education materials internally (n=63). Fifty-seven indicated they adapted materials from professional associations or other clinical guidelines, 36 from pharmaceutical manufacturers, and 28 indicated some other means of development.

When asked how discharge instructions and / or education materials were tailored to specific patient needs, 64 respondents indicated that they tailored by health literacy, 41 by limited-English proficiency (LEP), and 51 by preferred learning style.

Many organization indicated tailoring instructions for other indications, patient groups, and / or medical conditions (n=56). Specifically, more respondents indicated tailoring their materials by
clinical diagnosis (n=50); 38 reported tailoring them by procedure, 18 by patient groups, and 13 by co-morbidities.

Sixty-three percent of respondents reported evaluating their patient discharge instructions and / or education materials for readability, patient understanding and / or usability.

National Call for Examples
Organizations were asked to submit examples of their patient education and discharge instruction materials via a National Call for Examples. Overall a total of 35 organizations submitted examples of discharge instructions and/or education materials. Materials submitted included medication fact sheets, instruction sheets or booklets, patient discharge instructions or checklists, videos, or information gathered from patient education vendors or pharmaceutical websites.

Materials were reviewed with the primary focus to determine whether they contained relevant patient education components in several categories. These categories were derived from the literature and consistent with the environmental scan and recommendations from key stakeholders.3,5-7

- **Category 1: Anticoagulant basics**
  o Indicate the reason for initiating anticoagulation
  o Review the name of the anticoagulant drug (generic and / or trade), how it works
  o Onset of action, duration, dosing, frequency, potential drug interactions, storage, reversibility, duration of therapy
- **Category 2: Safety concerns**
  o Common signs and symptoms of bleeding and what to do when they occur
  o Common signs and symptoms of thrombosis and what to do when they occur
  o The need for birth control for woman of child-bearing age
  o Precautionary measures to reduce the risk of trauma or bleeding (e.g., shaving, brushing teeth, acceptable physical activities)
  o Common side effects or allergic-type reactions
- **Category 3: Communication with health care professionals**
  o Which health care providers (e.g., physicians, dentists) to notify of the use of anticoagulant therapy
  o When to notify an anticoagulation provider (dental, surgical, or invasive procedures or hospitalizations are scheduled)
  o Carrying identification (e.g., identification card, medical bracelet or necklace)
  o Using one pharmacy for all prescription drug needs
- **Category 4: Adherence**
  o Consequences of nonadherence or taking too much of the medication
  o When to take an anticoagulant medication what to do if a dose is missed
- **Category 5: Monitoring**
  o Periodic (six to 12 months) monitoring of renal function for DOACs
• The meaning and significance of the international normalized ratio (INR) for warfarin; the need for frequent INR testing and target INR values appropriate for treatment
• The narrow therapeutic index and the emphasis on regular monitoring to minimize bleeding and thrombosis risk

• Category 6: Diet and lifestyle
  • The influence of dietary vitamin K use and the need to limit or avoid alcohol

Most of the materials submitted were adapted from or referenced existing educational materials, such as those provided by pharmaceutical companies, patient education vendors (e.g., Micromedex® Patient Education, featuring CareNotes®, Krames Patient Education, Elsevier ExitCare), and other professional associations and stakeholders. While the level of specificity and comprehensiveness of the content differed among the submitted materials, almost all the materials covered the recommended patient education categories / components identified. Although the call for materials questionnaire specified a focus on patient discharge materials for anticoagulants other than warfarin, almost all the submitted materials addressed warfarin. In some cases, they only addressed warfarin (n=10), and in others warfarin was addressed in addition to other anticoagulants (e.g., apixaban, dabigatran, dalteparin, edoxaban, enoxaparin, fondaparinux, and rivaroxaban).

Project Conclusions and Recommendations
The use of DOACs in the treatment and prevention of VTE is changing how the condition is managed. While clinicians need to consider multiple factors to determine if DOACs are best for their patients, it is clear the patient also plays a key role in ensuring the safety and efficacy of DOAC use. Just as with warfarin, patients need to understand the risks and benefits associated with DOACs and how to manage their medication effectively and safely. Education can help patients understand the necessity of their medication as well as potentially prevent adverse medication events.

At the start of this project, the results of the environmental scan pointed to a dearth of knowledge about the role of patient education specifically for DOAC use. Many of the reviewed articles focused on warfarin when describing discharge instructions or patient education, which likely reflects the fact that, at the time of the publications, healthcare professionals were dealing with a mixed patient population that was receiving either a vitamin K antagonist (warfarin) or a DOAC for the same indications. While certain components of the medication management protocols associated with warfarin are not applicable for DOACs (such as INR monitoring), many of the recommended educational components (how to use the medications, need for compliance, symptoms and signs of bleeding) are similar among all anticoagulants. In addition, many safety concerns are similar for all anticoagulation therapy.

From our limited research, it appeared that the respondents were providing discharge instructions and / or education materials to their VTE patients being discharged on DOACs and other anticoagulants. While the level of detail and specificity differed, most of the materials submitted covered the components of patient education deemed to be most important by
professional associations and societies. More than half of the respondents (61%) reported providing discharge instructions and/or education materials based on preferred learning style (e.g., videos, one-to-one (verbal), and written materials). Respondents also reported tailoring of instructions and materials to limited-English proficient (LEP) patients, health literacy, or by diagnosis. These strategies are recommended by many professional associations to ensure patients are actively engaged in their care.6

The findings of our research did not point to a lack of available educational resources for DOACs use, nor did it point to ambiguity in what components of patient education should be included in discharge materials. In fact, both the questionnaires and submitted materials suggested an awareness of the importance of addressing safety concerns in patient education materials, as well as knowledge of available patient education resources regarding DOACs by those participating. In addition, a search of key stakeholders and professional association websites demonstrated numerous patient education resources available for use and adaptation by healthcare organizations to promote the safe and effective use of DOACs for VTE patients. As DOACs are still relatively new, more studies, evidence, and indications for safe use will continue to emerge. As such, it is important that both provider and patient education resources stay up-to-date and in step with professional and clinical recommendations. As healthcare organizations develop their own materials, they should ensure that recommended components are included, as well as tailoring materials to accommodate patient language and literacy levels, and preferred learning style (e.g., using multiple modalities of education).

To promote the need for up-to-date educational resources related to use of DOACs, and to promote the use of reliable materials, a compendium of resources from key stakeholders and relevant associations has been developed. While this compendium was developed to highlight DOAC-specific information, it also contains patient education materials for other anticoagulants (e.g., warfarin, LMWH) as well as general information about VTE. Healthcare organizations are encouraged to review these materials as they adapt or develop their own patient discharge instructions and/or education materials resources for VTE patients on anticoagulation therapy to be sure that the safety of DOAC use is kept at the forefront.

Limitations
The request for information primarily reached providers accredited or certified by The Joint Commission, or targeted organizations submitting measure information for the Joint Commission VTE measure set. As such, the results of the questionnaire cannot be considered representative of all healthcare organizations. In addition, the review of submitted materials was subjective and classifications were assigned based largely on the presence/absence of identified educational components and other parameters (e.g., provision of tailored materials). It is important to note that this review did not focus on other important components of discharge instructions and patient education, such as implementation practices and follow-up. In addition, this study was not designed to address the comparative effectiveness of education on treatment or safety.
References


Note: A comprehensive final report of all project related activities is available upon request.
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