

Volume 26, Issue 3

### July-September 2016

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## CANNT JOURNAL JOURNAL ACITN

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#### Co-Editors

Jovina Bachynski, MN, RN(EC), CNeph(C) T: (905) 845-2571 ext 6307 Email: cannt.journal1@gmail.com

Matt Phillips, MHS, RN T: (902) 473-7075 Email: cannt.journal2@gmail.com

Managing Editor Heather Coughlin, Pembroke, Ontario

Layout and Design Sherri Keller, Pembroke, Ontario

#### Advertising Sales

Heather Coughlin, Pappin Communications 84 Isabella St., Unit 2, Pembroke, ON K8A5S5 T: (613) 735-0952; F: (613) 735-7983 Email: heather@pappin.com Rate card: www.pappin.com

### **Letter from the Editors**

Welcome to the Summer 2016 issue of your *CANNT Journal!* We are excited to be able to share yet another instalment of meaningful and relevant articles to enhance and advance your nephrology practice. In this issue, we explore the emotional toll of end-stage renal disease, as well as another timely article on advanced care planning. The Continuing Education series offers a comparison of low molecular weight options for anticoagulant therapy.

Also in this issue is the last president's address from Anne Moulton. We would like to thank Anne for the leadership, dedication, and support that she has provided to the journal, the CANNT Board of Directors and, of course, the CANNT members over the past two years. We wish her luck as she attends the EDTNA/ERCA International Conference in Valencia, Spain, this September, and congratulate her on the honour of being a guest speaker at this international forum.

Finally, we would like to thank all those who are presenting poster and oral presentations at the upcoming CANNT National Conference 2016 in London. We are all looking forward to learning from you, and bringing back gems from across the country that we can incorporate into our own work settings. We would like to encourage all presenters from the national conference to consider submitting their work to the CANNT Journal for publication and, of course, we always welcome submissions from both seasoned, as well as budding professionals.

Matt Phillips and Jovina Bachynski CANNT Journal Co-editors

### **Call for CANNT Journal Editor**

The Canadian Association of Nephrology Nurses and Technologists (CANNT) Board of Directors is seeking to appoint a co-editor for the *CANNT Journal*. The co-editor would be supported by Pappin Communications, the journal's publisher.

The *CANNT Journal* is a peer-reviewed academic journal whose primary aim is to support CANNT's vision "as the keystone of excellence in nephrology nursing and technological care in Canada."

The co-editor's position entails interaction with authors, reviewers, editorial board members, publishers, and the CANNT Board of Directors, and is responsible for the overall quality of the journal content, with tasks including, but not limited to the following:

- · Solicitation and review of manuscripts
- Liaising with and supporting reviewers through the review process
- Communicating with and mentoring manuscript authors and regular column contributors
- Selecting and editing final manuscripts, submissions, and columns.

The co-editor must be a registered nurse, ideally, holding a Master's degree. A minimum of three years recent clinical nephrology experience and skills in research methodologies is required.

Candidates should submit a curriculum vitae together with a letter of no more than two pages summarizing the following:

- A statement describing the reasons for their interest in the position
- A vision for the future development of the *CANNT Journal*
- A short assessment of the skills you will bring to this position.

This is a volunteer position, however, an honorarium is provided annually. The closing date for applications is **November 30, 2016**. Please address all correspondence concerning this position to Heather Reid, CANNT Admin Assistant/Office Manager at **cannt@cannt.ca** 

### Mot des corédacteurs en chef

Bienvenue au numéro de l'été 2016 de votre Journal de l'ACITN! Nous sommes heureux de pouvoir partager une nouvelle série d'articles importants et pertinents visant à améliorer et à perfectionner votre pratique en néphrologie. Dans ce numéro, nous explorons notamment la charge émotive liée à l'insuffisance rénale terminale et présentons un article très à propos sur la planification des soins avancés. Notre série d'articles de formation continue offre une comparaison entre les différentes options de produits de faible masse moléculaire pour l'anticoagulothérapie.

Vous trouverez également dans ce numéro le dernier message d'Anne Moulton à titre de présidente de l'ACITN. Nous aimerions remercier Anne pour son leadership, son dévouement et l'aide apportée au Journal, au conseil d'administration de l'ACITN et, bien entendu, aux membres de l'ACITN au cours des deux dernières années. Nous lui souhaitons bonne chance pour sa participation, ce mois-ci, à la conférence internationale de l'EDTNA/ ERCA à Valence, en Espagne à titre de conférencière et la félicitons de ce grand honneur.

Enfin, nous aimerions remercier tous ceux et celles qui présenteront des affiches ou effectueront des présentations orales lors de l'imminente conférence nationale 2016 de l'ACITN à London. Nous nous réjouissons à l'idée de bénéficier de vos enseignements et de rapporter des joyaux d'un peu partout au pays en vue de les intégrer à notre propre milieu de travail. Nous invitons toutes les personnes qui présenteront leurs travaux lors de la conférence nationale à soumettre ces travaux au Journal de l'ACITN aux fins de publication. Il va sans dire que nous sommes toujours heureux de recevoir les soumissions de jeunes professionnels autant que celles de professionnels chevronnés.

### Matt Phillips et Jovina Bachynski Corédacteurs du Journal de l'ACITN

### **NOTICE BOARD**

- October 27–29, 2016. Canadian Association Nephrology Nurses and Technologists (CANNT) 49th National Symposium 2016—Changing the Face of Tomorrow, London, Ontario. www.cannt.ca
- November 15–20, 2016. American Society of Nephrology (ASN) Kidney Week 2016, McCormick Place, Chicago, Illinois. www.asn-online.org
- CANNT Vascular Access Guidelines: available now in the members only section at cannt.ca!

CANNT is asking for expressions of interest for co-chairs for the 2017 CANNT National Conference in Halifax, and the 2018 CANNT National Conference in Quebec City. If you are a CANNT member from either of these cities, please email your expression of interest to the CANNT office. Le Journal ACITN est la publication officielle de l'Association canadienne des infirmiers/ infirmières et technologues en néphrologie, a/s P.O. Box 10, 59 Millmanor Place, Delaware, ON NOL 1EO, téléphone : (519) 652-6767, télécopieur : (519) 652-5015, Courriel : cannt@cannt.ca. Publié quatre fois par année, ce journal est envoyé à tous les membres de l'Association. L'abonnement annuel est: Canada, 80\$ (+TVH), E.-U., 90\$, hors du Canada et E.-U., 115 \$. Les publications antérieures, lorsque disponsibles, coûtent 7,50 \$ (+TVH) chacune. Les opinions émises par les auteurs dans ce journal ne sont pas nécessairement partagées par l'Association ni par le corédactrices en chef. Nous invitons les lecteurs à nous faire part de leurs opinions. Toute correspondance devra être envoyée à l'ACITN, P.O. Box 10, 59 Millmanor Place, Delaware, ON NOL 1EO.

1-877-720-2819; Site web: www.cannt.ca

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#### Rédacteurs en chef

Jovina Bachynski, MN, RN(EC), CNeph(C) T: (905) 845-2571 ext 6307 Courriel : cannt.journal1@gmail.com

Matt Phillips, MHS, RN T: (902) 473-7075

Courriel: cannt.journal2@gmail.com Éditeur

Heather Coughlin, Pembroke, Ontario

Conception et design Sherri Keller, Pembroke, Ontario

#### Publicité

Heather Coughlin, Pappin Communications 84 Isabella St., Unit 2, Pembroke, ON K8A 5S5 T: (613) 735-0952; F: (613) 735-7983 Courriel : heather@pappin.com Publicité : www.pappin.com

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### Journal Editors/

Les rédacteurs en chef: Jovina Bachynski, RN(EC), MN-NP Adult, CNeph(C), T: 905-845-2571 ext. 6307 cannt.journal1@gmail.com

Matt Phillips, MHS, RN T: 902-473-7075 CANNT.journal2@gmail.com

### **Message from the President**

As I prepared to write this last message to you, I challenged myself to reflect not only on my CANNT activities over the past two years, but also on what key message I wanted to leave you with, as I near the end of my twoyear tenure as your CANNT President. As a registered nurse with 42 years of nursing experience, I have decided to speak briefly on the concept of "advocacy", a concept that has always been central to my nursing care.

Care of others is nursing's most basic tenet, in which patient advocacy is ethically grounded. Understanding the link between ethical issues and advocacy is paramount. The diverse nature of advocacy makes this concept complex but, as one of the key concepts of nursing ethics, it is an integral part of the professional nursing role in promoting a client's well-being. The provision of ethical care includes certain values such as client well-being, client choice, privacy and confidentiality, respect for life, truthfulness, and maintaining commitments and fairness—all integral components for a therapeutic client-nurse relationship. The context of ethics has traditionally been the overarching phenomenon of concern for nurses since the professionalization of nursing was expressed through the Nightingale pledge back in 1893. Nursing has since adopted an ethical framework into practice that has been expressed not only through provincial standards of practice, but also globally through the International Code of Nursing where standards of care on the rights of humans have been unequivocally outlined.

We are all taught that our professional obligation is to provide safe, ethical care and that advocating for patients' rights is part of this professional care. How we advocate for our patients, however, is unique and dependent on our strengths, interests, and experience. Advocacy is achievable at a micro, meso, and/or macro level. In the next few weeks, I will be speaking at the closing ceremony of the 45th European Dialysis and Transplantation (EDTNA/ERCA) International Conference in Valencia, Spain, as your CANNT representative and will, for the first time, be speaking to our international partners about collaboration in renal care. I feel extreme gratitude to be representing Canadian nurses and technologists at this international conference and see this event as an opportunity to advocate for our renal population through the exchange of knowledge, stories, and suggestions for continued collaboration that will ultimately benefit patient care.

I now challenge all of you to evaluate the ways you advocate for our renal patients, and identify opportunities to advocate even more. Upon closing, I want to thank you for electing me as CANNT President. It has been an extreme honour to serve on the CANNT Board of Directors and, although I will not be formally advocating for our patients as CANNT President, I will continue advocating for our patients for many more years ahead!

Respectfully, Anne

### PLEASE SEND ALL SUBMISSIONS, QUESTIONS, OR COMMENTS TO:

Jovina Bachynski and Matt Phillips, Co-Editors, CANNT Journal: Jovina Bachynski: **CANNT.journal1@gmail.com** Matt Phillips: **CANNT.journal2@gmail.com** 

### Le mot de la présidente

Alors que je me préparais à vous écrire ce dernier message, je me suis mise au défi de réfléchir non seulement à mes activités au sein de l'ACITN au cours des deux dernières années, mais également au message fondamental que je voulais vous laisser à l'approche de la fin de mon mandat de deux ans comme présidente de l'AC-ITN. En tant qu'infirmière autorisée possédant 42 années d'expérience en soins infirmiers, j'ai décidé de vous parler brièvement du concept de « défense des droits des patients », un concept qui a toujours été au cœur de mon travail comme infirmière.

Prendre soin d'autrui représente le principe fondamental des soins infirmiers, et la défense des droits des patients se fonde sur ce principe d'un point de vue éthique. La compréhension du lien entre les enjeux éthiques et la défense des droits des patients est d'une importance capitale. La nature diversifiée de la défense des droits des patients en fait un concept complexe, mais puisqu'il s'agit de l'un des concepts clés de l'éthique des soins infirmiers, il fait partie intégrante du rôle de la profession infirmière dans la promotion du bien-être des patients. La prestation de soins éthiques comprend certaines valeurs comme le bienêtre des patients, le respect de leurs choix, le respect de la vie privée et de la confidentialité, le respect de la vie, l'honnêteté, l'impartialité et le désir de maintenir ses engagements, valeurs qui font partie intégrante de la relation entre les infirmiers et infirmières et leurs patients. Le contexte de l'éthique a toujours été la principale source de préoccupation des infirmiers et infirmières depuis l'expression de la professionnalisation des soins infirmiers dans le serment de Nightingale en 1893. La profession infirmière a depuis adopté un cadre éthique dans sa pratique, cadre qui se reflète non seulement dans les normes de pratique provinciales, mais également à l'échelle mondiale dans un code d'éthique international, où les normes de soins sur les

droits de la personne ont été définies sans équivoque.

On nous enseigne que nous avons l'obligation professionnelle de fournir des soins sécuritaires et éthiques et que la défense des droits des patients fait partie de ces soins professionnels. Toutefois, la façon dont nous défendons les droits de nos patients est unique et varie en fonction de nos forces, de nos intérêts et de notre expérience. Il est possible de défendre les droits des patients à petite, moyenne et grande échelle. D'ici quelques semaines, je prononcerai une conférence à la cérémonie de clôture de la 45e conférence internationale de l'EDTNA/ERCA à Valence, en Espagne en tant que représentante de l'AC-ITN. Pour la première fois, je parlerai à nos partenaires internationaux de collaboration en néphrologie. Je me sens extrêmement reconnaissante de représenter les infirmiers et infirmières ainsi que les technologues du Canada à l'occasion de cette conférence internationale et je vois cet événement comme une occasion de défendre les intérêts de nos patients en néphrologie grâce au partage de connaissances, d'expériences et de suggestions en vue d'assurer une collaboration continue qui, au bout du compte, permettra d'améliorer les soins aux patients.

Je vous mets maintenant au défi d'évaluer la façon dont vous-mêmes défendez les droits de vos patients atteints d'insuffisance rénale et de déterminer ce que vous pourriez faire de plus en ce sens. Pour conclure, j'aimerais vous remercier de m'avoir élue comme présidente de l'ACITN. J'ai été extrêmement honorée de siéger au conseil d'administration de l'ACITN et, même si je ne représenterai plus officiellement nos patients à titre de présidente, je continuerai de défendre leurs droits pendant de nombreuses années encore!

#### Respectueusement, Anne

### CANNT REPRESENTATIVES/ CONTACTS; REPRÉSENTANTS/ CONTACTS ACITN

CNA Liaison/Liaison pour AIIC : Anne Moulton, RN, BScN, MN, CNeph(C) T: 905-522-1155 x33916 amoulton@stjosham.on.ca

Kidney Foundation of Canada, MAC Representative/Fondation du rein—Comité de médical consultatif: Anne Moulton, RN, BScN, MN, CNeph(C) T: 905-522-1155 x33916 amoulton@stjosham.on.ca

Bursary Committee/ Comité des Bourses : Anne Moulton, RN, BScN, MN, CNeph(C) T: 905-522-1155 x33916 amoulton@stjosham.on.ca

CANNT Administrative Office/ Bureau National de l'ACITN : PO Box 10, 59 Millmanor Place Delaware, ON NOL 1E0 New phone: 519-652-6767 Same Toll Free: 877-720-2819 New fax: 519-652-5015 General email: cannt@cannt.ca

Contacts: Sharon Lapointe, Manager, Member Services sharon@cannt.ca

Susan Mason Manager, Website and Social Media susan@cannt.ca

Heather Reid National Administrator/Board heather@cannt.ca

2016 Symposium: October 27–29, 2016 London, Ontario Heather E. Reid, ARCT, MSc Principal Planner & Owner Innovative Conferences & Communications PO Box 319, 59 Millmanor Place Delaware, ON NOL 1E0 T: 519-652-0364 F: 519-652-5015 hreid@innovcc.ca Website: www.innovcc.ca

Journal advertising contact/Personne contact pour la publicité du Journal : Heather Coughlin Pappin Communications, 84 Isabella Street, Pembroke, ON K8A5S5 T: 613-735-0952; F: 613-735-7983 heather@pappin.com Rate card: www.pappin.com

### Your Board in Action

### CANNT 2016: CHANGING THE FACE OF

### TOMORROW, LONDON, ONTARIO

A three-day, jam-packed conference for nephrology healthcare professionals across Canada. Education sessions, networking opportunities, exhibit hall, plenary sessions, social evening, and the all-important meals!

It just happens! Well, not exactly. Let's rewind and examine what goes into hosting a conference of this magnitude.

The CANNT Board decides on the host city at least three years in advance. Our expert event planner, Heather Reid, and her team at Innovative Conferences & Communications start sourcing out venues. They consider location, budget, transportation, exhibit space, meals, and hotel space. The event planner negotiates contracts. The board is then presented with the options and narrows it down to a couple of choices. A site visit is conducted by the event planner to ensure that the space meets all our needs.

The CANNT Board then advertises for a conference planning committee chair or co-chairs. They, in turn, seek out committee members in the host area. The goal is to assemble a diverse group to organize the different education streams. A CANNT Board member from the host region also sits on the planning committee and acts as a liaison to the board.

The planning committee has regular teleconference calls with the event planner, who adheres to rigid timelines to ensure that all the details are completed.

The first task for the planning committee is to establish a theme, a snappy title, and beautiful posters. This is done with multiple brain storming emails, which include graphics of different poster ideas.

The conference is then planned around the theme. A call for abstracts, sponsorship packages, and information about awards and bursaries goes out to our members and nephrology healthcare professionals across Canada.

Corporate sponsorship is so important to our conferences, and we have been very fortunate to receive ongoing support from many companies. The planning committee plays a key role contacting companies in their area.

The planning committee promotes their upcoming conference by setting up a booth in the exhibit hall. They also provide a short presentation, as the last item of the CANNT conference. They extend an invitation to members and show a short video highlighting attractions in their city.

All the abstract and poster submissions go through the CANNT office. They are then distributed to the planning committee. Each member reviews the submissions, assessing quality and relevance to the conference theme.

There is one face-to-face meeting with the event planner in the host city. This is usually TWO LONG days of making many BIG decisions. Together, the submissions are again reviewed and plotted into the appropriate timeframe and education stream. This process allows the committee to see which education streams are lacking or to encourage some poster presentations to become oral presentations. Once the preliminary program is set, individuals are notified and asked to make their own arrangements to attend. Some employers provide funding to individuals once they know they have been asked to present.

The evening of entertainment is also discussed and a preliminary plan is established. The event planners help organize this evening. However, it is up to the planning committee to keep it running smoothly.

The budget is considered in all decisions. The CANNT Board strives to provide to its members the best conference experience, while keeping the cost affordable for our members. This is the toughest task for any planning committee.

The remainder of the work is once again completed by teleconference and email. The event planner keeps the planning committee and CANNT Board members up to date with all aspects of the conference, and seeks direction with any decisions.

The upcoming conference is advertised through the *CANNT Journal*, CANNT website, emails, and the use of social media.

The planning committee, with the assistance of the CANNT Board, provides support to the event planners throughout the three-day conference.

Each member is given a folder with a schedule of duties and timelines. This system works very well. There is no question where you need to be, when you need to be there, and what you will be doing when you arrive.

There is a great sense of accomplishment when you see it all come together. There is no greater satisfaction than a sincere "thank you" from a conference attendee.

All members, including members of the planning committee, are asked to complete a survey about the conference experience. All feedback is reviewed and carefully considered in the hopes of making next year's conference experience even better.

CANNT Board members and planning committee members are all volunteers. They give hours and hours of their time to share their passion for nephrology and the CANNT organization. None of this would happen without volunteers!

So why would someone sign up to volunteer? Great question!

Volunteering comes with benefits: gaining confidence, meeting new people, learning new skills, leadership, challenging oneself, responsibility, being part of an organization you believe in and, most importantly, having fun!

Volunteering is your opportunity to do extraordinary things!

Remember when you're enjoying your next conference experience—it did not just happen!

Yours in nursing, Heather Dean, RN, CNeph(C) CANNT President-Elect

### The emotional toll of end-stage renal disease: Differentiating between social isolation, loneliness, and disengagement

By Julie Leming

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### ABSTRACT

The terms social isolation, loneliness, and disengagement are used frequently in chronic illness with little consensus about the meaning and association between them. Examining the concepts provides a greater understanding of the role each plays in the well-being of patients and guides health care workers in prevention and early recognition. This article presents a modified version of Walker and Avant's (2011) method of concept analysis to differentiate and identify the most appropriate ways to study and overcome the various challenges facing patients with end-stage renal disease. Defining attributes, antecedents, and consequences are identified. Further illustration of the concepts is provided using a side-by-side comparison including preventive considerations and nursing action plans.

Humans have an innate need to engage with others, to communicate interpersonally, and to participate in mutually satisfying relationships (Linz & Sturm, 2013). This engagement is particularly important for patients managing severe or long-term health problems such as end-stage renal disease (ESRD). Long-term management affects every aspect of the patient's life: physical, financial, social, and emotional. Three similar but distinct concepts are often offered as a basis for evaluating interpersonal relationships; they are social isolation, loneliness, and disengagement (Coyle & Dugan, 2012; Dury, 2014; Johnson & Mutchler, 2014; Stein & Tuval-Mashiach, 2014). When nurses encounter patients in the throes of managing chronic kidney disease, they have important questions to consider: If you are facing social isolation, are you automatically lonely? Can you be lonely when you have a large social network? Is disengagement automatic or even probable when you are facing social isolation and/or loneliness? Exploring how these three concepts may affect each other must begin with a clear understanding of what each one means and how they are the same or different.

A concept analysis helps clarify ambiguous concepts by producing an operational definition, defining attributes, antecedents, and consequences (Walker & Avant, 2011). This paper presents a comparative concept analysis on social isolation, loneliness, and disengagement to define

### **ABOUT THE AUTHOR**

Julie Leming, MSN, RN, CNE, PhD Candidate, University of Texas at Tyler

jleming@patriots.uttyler.edu

each, and differentiates them from one another. A modified version of the Walker and Avant (2011) method is utilized for this analysis. Differentiation of the concepts is particularly important in planning research with chronic kidney disease, so that targeted measurements and interventions can be aimed at the exact problem with the most potential to actually help the situation. Using the terms interchangeably is a disservice if their meanings are singularly different, and it confounds possible interventions and solutions. The purpose of this paper is two-fold: to differentiate the terms and to identify the most appropriate term for studying the various challenges for patients facing long-term, debilitating disease management.

#### SOCIAL ISOLATION

Social isolation has been the subject of research for a number of years, yet there remains a degree of inconsistency in how it is defined and measured. In spite of the technological advances of the recent decades, human social relationships remain a significant issue affecting the physical and psychosocial health of many populations. Studies have associated social isolation with severe mental illness (Linz & Sturm, 2013), mortality (Pantell et al., 2013), increases in systolic and diastolic blood pressure (Shankar, McMunn, Banks, & Steptoe, 2011), and perceived stress (Webel et al., 2014). It has been used synonymously with social support and small social networks (Nicholson, 2009), and classified as both objective (Linz & Sturm, 2013; Shimada et al., 2014) and subjective (Hawthorne, 2008; Nicholson, 2009; Warren, 1993). A lack of a consistent definition of the concept makes measurement difficult and fosters use of various measures, which can result in conflicting data (Pettigrew, Donovan, Boldy, & Newton, 2014).

#### **Concept Identification**

The *Merriam-Webster Dictionary* does not define social isolation as a construct, but defines each term individually. Social is defined as "tending to form cooperative and interdependent relationships with others" ("Social", n.d.,). Social appears to be the opposite of isolation with its focus on relationships with others. Isolation is defined as "the state of being in a place or situation that is separate from others" ("Isolation", n.d.). Merriam-Webster also provides medical definitions of "a segregation of a group of organisms from related forms in such a manner as to prevent crossing" and "a psychological defense mechanism consisting of the separating of ideas or memories from the emotions connected with them" ("Isolation", n.d.). All of these definitions have a predominant theme of separateness.

Social isolation has been studied in the severely mentally ill and is defined as "a state of being unintentionally alone, with a lack of fulfilling social connection, resulting in the subjective experience of loneliness and distress" (Linz & Sturm, 2013, p. 245). Linz and Sturm (2013) identify three constructs of social isolation that relate to severe mental illness: stigma, alienation, and loneliness. These notions of stigma, alienation, and loneliness are echoed in Pollack's (2009) work on criminalized women. In a concept analysis of social isolation in older adults, Nicholson (2009) proposed that it is "a state in which the individual lacks a sense of belonging socially, lacks engagement with others, and has a minimal number of social contacts and they are deficient in fulfilling and quality relationships" (p. 1346). Dury (2014) utilizes the same three ideas when studying the elderly. Another study defines social isolation as having limited contact with people and loneliness or perceived social isolation as the psychological counterpart (Shankar et al., 2011), whereas Pettigrew et al. (2014) outline two separate components of social isolation: objective and subjective. Finally, Zavaleta, Samuel, and Mills (2014) define social isolation as the lack of quality and quantity of social relationships with other people at the different levels of human interaction, such as individual, group, community, and the larger social environment. These definitions focus on the idea of separateness from the group.

### **Defining Attributes**

Defining attributes are the characteristics that are most frequently associated with the concept of social isolation. When listed, the defining attributes should immediately bring the concept to mind (Walker & Avant, 2011). The defining attributes of social isolation are:

- lack of quality relationships with persons in social network
- lack of engagement with others
- absence of a sense of belonging
- lack of fulfilling relationships.

The number of members of the social network is less important than the quality of the relationships with the members of the social network. One can have a large social network and, yet, still experience social isolation if the members of the network are unreliable, uncaring, or provide only superficial relationships (Nicholson, 2009). Lack of engagement can be failure to call friends or family, or being unable or unwilling to contact because of other barriers such as the inability to use the telephone or fear that friends are uninterested in hearing the details of what is being experienced. One can be in a room full of people yet not engage in socialization and, therefore, be socially isolated. The need for love and a sense of belonging is a basic human need, which prevents a person from feeling or being socially isolated. Absence or lack of fulfilling relationships is an attribute of social isolation because one can socially engage with others without feeling fulfilled and still feel socially isolated.

Although launching new friendships may be more challenging later in life, there is a need to join with others who think in a similar way and can be trusted (Pettigrew et al., 2014) and to strengthen relationships based on shared experience (Stein & Tuval-Mashiach, 2014).

### **Antecedents and Consequences**

Antecedents are those events or circumstances that must be in place prior to the manifestation of the concept (Walker & Avant, 2011). Antecedents related to social isolation include a prohibitive environment and physical and psychological barriers (Nicholson, 2009). Restrictions imposed by dialysis schedules (Tanyi & Werner, 2008; Yodchai, Dunning, Hutchinson, Oumtanee, & Savage, 2011), physical effects of headache, nausea, fatigue, and weakness, as well as anger and depression, impact social activity (Başkale & Başer, 2011), thus increasing the risk for social isolation in those living with ESRD. Consequences are those events that occur because of the concept. Consequences of social isolation include development of negative coping strategies (Warren, 1993), and cardiovascular disease, diabetes, smoking, and depression (Cacioppo & Cacioppo, 2014) and loneliness (ElSadr, Noureddine, & Kelley, 2009). Social isolation definitely depends on an unfulfilled need of some kind involving other persons, but it is unclear if it is the same as loneliness or if loneliness is an inevitable outcome.

### LONELINESS

The concept of loneliness is similar to social isolation, but there are distinct and important differences. Studies show a correlation between loneliness and fatigue with self-care with hemodialysis patients (Akin, Mendi, Ozturk, Cinper, & Durna, 2013), as well as sexual frequency, communication, satisfaction, avoidance and sensuality (Koç & Saglam, 2013). Loneliness has also been associated with the reporting of a mental health diagnosis (Coyle & Dugan, 2012), as well as depression, social isolation, and greater likelihood of specific negative health behaviours (Shankar et al., 2011). Loneliness may be more of a personal feeling than social isolation, which is reflected by a more external focus.

### **Concept Identification**

Loneliness is defined by *Merriam-Webster* as "being without company," "cut off from others," "sad from being alone," and "producing a feeling of bleakness or desolation" ("Loneliness", n.d.). Peplau and Perlman (1982) suggest that loneliness is a subjective experience resulting from a deficiency in social relationships. It is a product of individual valuation of the number of interpersonal relationships, the quality of those relationships, and individual standard for those relationships (Coyle & Dugan, 2012; de Jong Gierveld, Keating, & Fast, 2014). Hence, loneliness is not a factor of having no or few friends or visitors; it is more akin to a feeling of dissatisfaction with the quality, number, and/ or frequency of interactions, which leaves one with negative feelings such as sadness, anger, hostility, futility, abandonment, or guilt.

### **Defining Attributes**

The defining attributes of loneliness are:

- sense of alienation
- interpersonal isolation
- distressed reactions.

A sense of alienation involves a feeling of separation or estrangement, and may be from one's self (Bekhet, Zauszniewski, & Nakhla, 2008) or from others (Kvaal, Halding, & Kvigne, 2013; Stein & Tuval-Mashiach, 2014). In a study on Israeli veterans of combat and captivity, the sense of alienation was described as living in "a different world" and "not connected to anything" (Stein & Tuval-Mashiach, 2014, p. 4). Bekhet et al. (2008) describe the self-alienation as having two components: emptiness and depersonalization. Interpersonal isolation refers to the feeling of being alone, which can be social, geographic, or emotional in nature (Bekhet et al., 2008; Kvaal et al., 2013). It is important to note that interpersonal isolation refers to a feeling, and that even one with many social connections may still experience loneliness (Coyle & Dugan, 2012). Distressed reactions may be physiological, behavioural (Bekhet et al., 2008), or psychological (Coyle & Dugan, 2012). These reactions may also include headaches and upset stomach (Bekhet et al., 2008), depression (Shankar et al., 2011), and decrease in self-care (Akin et al., 2013).

### **Antecedents and Consequences**

The primary antecedents of loneliness are a personal dissatisfaction with the quality of one's interpersonal relationships (ElSadr et al., 2009) and the inability to reach out or see the need to reach out to others for help (Coyle & Dugan, 2012). Consequences of loneliness include: negative emotions (Kvaal et al., 2013), decrease in self-care (Akin et al., 2013), passivity in social interactions (Qualter et al., 2015), lower self-reported health measures and increased reporting of mental health diagnosis (Coyle & Dugan, 2012), and depression (Shankar et al., 2011). The negative and more passive reaction to feelings of loneliness may set the stage for a person to actually disengage from the social structure.

### DISENGAGEMENT

A broad understanding of disengagement is essential for nurses caring for clients with ESRD because they are in a unique position to assess disengagement capacities of patients. Patients with poor disengagement capacities may be more likely to experience depressive symptoms than those with better disengagement capacities (Dunne, Wrosch, & Miller, 2011). Other than the primary caregiver, nurses often have the most contact with patients with chronic illness. In order to provide holistic care and ensure patients maintain optimal well-being, nurses must evaluate patients at each encounter for disengagement and make appropriate referrals where disengagement is maladaptive or debilitating.

Disengagement theory is a social-psychological theory of aging that suggests that disengagement is the inevitable

process of dissolving relational ties between a person and society; some consider it a normal part of the aging process (Johnson & Mutchler, 2014; Reed, 1970). It has been contrasted with continuity theory, which suggests that healthy aging requires continuing previous roles or similar roles to maintain a positive contribution to society. A third theory on aging, which is in contrast to disengagement theory, is activity theory. Activity theory suggests that successful aging occurs when the elderly participate in new activities to help avoid motivation toward disengagement (Robinson & Stell, 2015).

### **Concept Identification**

The Merriam-Webster Dictionary defines disengage as "to separate from someone or something, to stop being involved with a person or group, to stop taking part in something" ("Disengage", n.d.). In their concept analysis on connection in older adults, Stovall and Baker (2010) cite bond and association as defining attributes of connection. Connection might be considered contrary to disengagement. In the literature, disengagement is largely discussed as the response to a threat to one's self-esteem or social identity, and refers to disengaging from a particular domain (Cheng & McCarthy, 2013; Leitner, Hehman, Deegan, & Jones, 2014) or a particular group in which one experiences negative stereotypes (Pagliaro, Alparone, Pacilli, & Mucchi-Faina, 2012). Psychological disengagement involves using discounting and devaluing as an approach for dealing with differential treatment and other factors based on groups (Laplante, Tougas, Lagacé, & Bellehumeur, 2010). One study defined disengagement as a dissociation of self-esteem from feedback received (Tougas, Rinfret, Beaton, & de la Sablonnière, 2005). Leitner et al. (2010) use the term *adaptive disengagement* to describe disengagement across a variety of situations and domains in response to environmental cues, which are not limited to stigmatized feedback.

#### **Defining Attributes**

Defining attributes of disengagement are:

- dissociation from a particular group or domain
- absence of association or bond with others.

Dissociation from a particular group or domain may include work, volunteerism, civic organizations, social networks, and goals, which become perceived as unattainable (Laplante et al., 2010; Wrosch, Rueggeberg, & Hoppmann, 2013). This dissociation may be an attempt to buffer the emotional consequences of discrimination, negative feedback, or personal failure. However, in other circumstances, it may be an endeavour to find respite and replenish personal resources (Coyle & Dugan, 2012). Absence of association or bond with others may be evidenced by not thinking about a particular domain or by physically withdrawing from a particular domain or group (Wrosch et al., 2013). Adaptive disengagement may be seen as a self-protective process (Leitner et al., 2014) when remaining part of the group or process is seen as too overwhelming or threatening to continue.

#### **Antecedents and Consequences**

The precursors of disengagement include a perceived threat to one's self-esteem or social identity, discounting feedback, and devaluing the domain. Perceived threats to one's self-esteem or social identity vary between individuals and over the life span. The elderly are at risk for threats related to ageism in addition to disabilities associated with many chronic illnesses. Discounting feedback refers to attributing less credibility to negative feedback received, whereas devaluing refers to withdrawal from a particular domain or group, generally after discounting has occurred (Laplante et al., 2010). Consequences or the possible outcomes of disengagement depend on whether disengagement is adaptive or maladaptive. Consequences of adaptive disengagement include maintaining social identity, increased stress management, increased multiple role management, recovering personal resources (Cheng & McCarthy, 2013), and reduced negative mood and increased overall well-being (Dunne et al., 2011). Consequences of maladaptive disengagement are role conflict, poor stress management, feelings of failure, loneliness, and depression. Whether the disengagement is adaptive or maladaptive depends on the perception of the person involved. For all three concepts (social isolation, loneliness, and disengagement), nursing actions are focused on mitigating the negative aspects or outcomes associated with the concept.

### **CONCEPT COMPARISON**

Although all three concepts have a negative connotation associated with each in some way, there do appear to be distinct levels of intensity and varied need for action. Social isolation is having inadequate quality and quantity of social relations with other people. It is manifested as an **involuntary** loss of one's ability to affiliate with a group. An elderly man whose last close friend has just died might find himself socially isolated because of his thrice-weekly hemodialysis schedule. Disengagement is similar to social isolation, but it manifests as the **voluntary** withdrawal from groups. It might be considered as a mental or physical process that occurs in response to a threat to one's self-esteem or social identity. Although it might be voluntary, withdrawal could still be seen as desirable or undesirable by the individual. An aging woman might drop out of her book club due to post-dialysis fatigue. Both social isolation and disengagement are distinct from loneliness, which is a measure of one's reaction to the quality of relationships or the absence of the relationships. Loneliness is a negative emotion that sometimes results from social isolation or disengagement, but it can also be present when neither of these other situations exists. One can be lonely in the midst of other people if no personal joy or satisfaction is perceived to be possible. Although all three concepts have a degree of negativity associated with them, it seems clear that how the person reacts to the situation is the key to long-term consequences and appropriate nursing interventions. There also appears to be an implied sequence to the concepts, although it is not finite

or inevitable. The level at which one is able to adapt to the situation appears to influence whether it has a negative (maladaptive) or neutral (adaptive) effect. Because of the negative aspect of the overarching idea of being alone, no positive aspects were identified. At best, adaptation to the situation could be seen as possibly "not negative," but it is doubtful if any of the concepts could be portrayed as positive. Even the elderly lady who disengaged from her book club might find relief from the gossip (a neutral response), but not necessarily happiness at her loss of social interaction. Table 1 provides a comparison of the three concepts.

### CONCLUSIONS AND RECOMMENDATIONS

The debilitating effects experienced by individuals with ESRD negatively impact their physical and socio-emotional well-being Early recognition of restrictive environments, personal dissatisfaction with interpersonal relationships, and perceived threats to self-esteem or social identity allow for intervention and prevention of long-term mental and physical consequences. All patients with ESRD should be evaluated for social isolation, loneliness, and disengagement. Comprehensive assessment of social network on admission to acute care facilities can provide discharge planners with vital information and time to make appropriate referrals to community groups. Online support groups exist for a number of chronic diseases and may be a viable alternative when physical barriers prevent face-to-face social interaction. Education regarding online safety and follow-up are required to ensure the effectiveness of online support groups. For patients unable to safely access online support, face-to-face support groups are available in many communities. Nurses in outpatient settings such as pre-dialysis clinics or dialysis units can ask probing questions while providing care: Do you have friends you talk with? Do you feel lonely? How much time do you spend alone? What do you do when you're alone? These questions not only provide the nurse with insight on the patient's socio-emotional status, but may also foster an improved nurse-patient relationship, as the patient perceives caring from the nurse. Answers to these questions can help the nurse determine if further evaluation of social isolation, loneliness, or disengagement is needed.

Further research is needed to develop effective interventions to mitigate social isolation, loneliness, and disengagement in the elderly with ESRD. Comparative studies are needed to establish the effectiveness of online interventions and low-cost face-to-face interventions and also to determine access and safety issues with online interventions for this patient population in rural and urban areas. Quantitative studies are needed to evaluate the effects of these concepts on self-care and disease management. Longitudinal studies are needed to better understand socio-emotional issues faced over the trajectory of chronic illness. As the ESRD population continues to grow, development of interventions to improve their well-being will benefit the patient and family, the health care delivery system, and society in general.

Characteristics	Social Isolation	Loneliness	Disengagement
Defining Attributes	<ul> <li>Lack of quality relationships with members of a social network</li> <li>Lack of engagement with others</li> <li>Absence of sense of belonging</li> <li>Lack of fulfilling relationships</li> </ul>	<ul> <li>Sense of alienation</li> <li>Interpersonal feeling of isolation</li> <li>Distressed reactions</li> </ul>	<ul> <li>Dissociation from a particular group or domain</li> <li>Absence of association or bond with others</li> </ul>
Patient Situation	<ul> <li>Involuntary loss of group affiliation</li> </ul>	<ul> <li>Reaction to loss of group affiliation</li> </ul>	<ul> <li>Voluntary withdrawal from group(s)</li> </ul>
Possible Causes (Antecedents)	<ul> <li>Prohibitive or restrictive environment or circumstances</li> <li>Physical or psychological barriers</li> </ul>	<ul> <li>Personal dissatisfaction with the quality of interpersonal relationships</li> <li>Inability to reach out or to see the need to reach out to others</li> </ul>	<ul> <li>Perceived threat to self- esteem or social identity</li> <li>Discounting and devaluing the domain</li> </ul>
Preventive Considerations	<ul> <li>Change environment – address reasons for restrictions</li> <li>Change physical limits—recovery, therapy or rehabilitation to decrease limitations</li> <li>Change attitude – identify psychological issues and refer for assistance</li> </ul>	<ul> <li>Explore new group options for association</li> <li>Determine if loneliness is perceived as a problem to patient</li> </ul>	<ul> <li>Help client deal with threat</li> <li>Understand why domain is/has become undesirable</li> <li>Accept patient decision to withdraw is a possibility</li> </ul>
Outcomes (Consequences)	<ul> <li>Negative coping skills; mental and psychological threats; chronic disease susceptibility; loneliness</li> </ul>	<ul> <li>Feeling empty; confused identity; distressed reactions; negative emotions; self-care deficits; passive in social interactions; low health perception; mental health manifestations; disengagement; depression</li> </ul>	<ul> <li>Social identity; able to manage stress and multiple roles; recovery of personal resources; satisfaction or dissatisfaction with social support; role conflict; feelings of failure; loneliness; depression</li> </ul>
Nursing Action Plan	<ul> <li>Social isolation is identifiable to the nurse when the patient or caregiver comments on how alone or isolated they feel.</li> <li>Simple referral to a support group may not work if there are mobility restrictions, so online resources might be an option</li> </ul>	<ul> <li>Loneliness is sometimes identifiable through patient or caregiver comment but often must be investigated by the nurse. A variety of loneliness scales are available. Exploration into the nature of the source of loneliness can provide direction for referral and intervention. Meals on Wheels might be a low cost intervention</li> </ul>	<ul> <li>Disengagement is the result of stressors or threats in the patient's life. The ability to adaptively disengage can be measured on a brief scale, or the patient and caregiver can be questioned specifically to determine if situation needs intervention. Depending on severity, referral can be made to online support groups</li> </ul>

#### Table 1: Specific Characteristics of Social Isolation, Loneliness, and Disengagement

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### Low molecular weight heparin for the treatment of deep vein thrombosis and pulmonary embolism in patients with chronic kidney disease

By Jennifer Ma and Marisa Battistella

#### **OBJECTIVES**

After reading this article, the reader will be able to:

- 1. Compare and contrast the pharmacokinetics of different low molecular weight heparins (LMWH)
- 2. Discuss the evidence surrounding the use of LMWH in patients with chronic kidney disease (CKD)
- 3. Discuss how to monitor a CKD patient who is initiated on LMWH

Venous thromboembolism (VTE) affects approximately 1–2 in 1,000 Canadians each year, with one-third of the patients presenting due to a pulmonary embolism (PE) and the remaining due to deep vein thrombosis (DVT). Up to 10% of these PEs can be fatal within the first hour of symptoms, making prompt diagnosis vital to treatment success (Thrombosis Canada, 2013). Following a thrombotic event, patients are typically initiated on an oral anticoagulant. Although a number of new oral agents exist, warfarin is the only agent that is not contraindicated in end-stage renal disease, making it the treatment of choice in this patient population. If warfarin is not tolerated or there is a contraindication to its use, low molecular weight heparin (LMWH) serves as an alternative option (Hughes, Szeki, Nash, & Thachil, 2014). The use of LMWH in patients with CKD is often cautioned against, as these agents are renally cleared and relatively contraindicated due to concerns surrounding drug accumulation and an increased risk of bleeding (Saltiel, 2010). Although there is some evidence reporting the safe use of LMWH for VTE prevention and preventing circuit thrombosis in hemodialysis patients (Chan, Thadhani, & Maddux, 2013; Lim, Cook, & Crowther, 2004), there remains limited evidence for use in patients with chronic kidney disease (CKD) for VTE treatment. This article will address this issue through reviewing the pharmacokinetics of the different LMWH, as well as the literature evidence.

### **ABOUT THE AUTHORS**

Jennifer Ma, BScPhm, PharmD, Pharmacy Resident, University Health Network, Toronto, ON

Marisa Battistella, BScPhm, PharmD, ACPR, Clinician Scientist, Assistant Professor, Leslie Dan Faculty of Pharmacy, University of Toronto, Clinical Pharmacist – Nephrology, University Health Network, Toronto, ON

### Although different LMWHs are generally comparable

PHARMACOKINETICS OF LMWH

clinically, they have different molecular weights, which affect their kinetic properties. The mechanism by which LMWH causes anticoagulation is through the inhibition of coagulation factors Xa and II (Figure 1). The molecular weight affects the specificity that each LMWH has to binding factor Xa or II, with smaller molecular weights selectively targeting factor Xa compared with factor II. This, in turn, influences the

Figure 1: The three pathway	s that make up the
classical blood coagulation	pathway



(Adapted from reference: Pallister & Watson, 2010)

#### Table 1: Properties of LMWH

	Enoxaparin	Dalteparin	Tinzaparin
Half-life (hours)	4.5	4.0	3.4
Bioavailability (%)	91	87	87
Anti-Xa/anti-IIa ratio	3.8	2.7	2.8
Average Molecular Weight (daltons)	4500	5000	5500–7500
Relative Renal Elimination	+++	++	+

(Hughes et al., 2014; Merli et al., 2010)

bioavailability and half-life of the LMWH (Table 1). Renal clearance is also indirectly proportional to the molecular weight of the LMWH. Therefore, accumulation may be more pronounced in a LMWH with a smaller molecular weight (Hughes et al., 2014). This article will address three LMWHs: enoxaparin, dalteparin, and tinzaparin.

### Enoxaparin

Enoxaparin is the most widely studied LMWH, with most of the data stemming from its use in cardiovascular trials. An analysis of renally-impaired patients (creatinine clearance [CrCl]  $\leq$ 30ml/min) in two of these major trials showed a significantly higher risk of bleeding compared to patients with normal renal function (Spinler et al., 2003). Enoxaparin also has the smallest molecular weight, making its renal clearance the most prominent of the agents discussed (Table 1). Due to the increased risk of bleeding from potential accumulation in renal impairment, a dose reduction is recommended in all patients with a CrCl <30 ml/min with a recommended dose of 1 mg/kg once daily in the treatment of VTE (Table 2) (Sanofi Canada, 2014).

### Dalteparin

Dalteparin has been shown to be safely used for thromboprophylaxis in renally-impaired patients with a CrCl < 30ml/min at a dose of 5,000 units once daily (Douketis et al., 2008), but there have been no trials studying its use in the treatment of VTE. The recommended dose for the treatment of VTE in non-renally-impaired patients is 200 units/kg once daily, but due to the lack of evidence, there are no recommended dose adjustments for this indication in renally-impaired patients. Taking into account its pharmacokinetics, dalteparin has the second largest molecular weight and a clearance that is less dependent on renal function compared with enoxaparin (Table 1).

### Tinzaparin

Tinzaparin has been studied in elderly patients with moderate renal impairment (CrCl 20-50ml/min). Patients in these studies were safely administered a standard dose of

#### Table 2: Dosing of LMWH

	Enoxaparin	Dalteparin	Tinzaparin
Dose for treatment of VTE	1 mg/kg twice daily	200 units/kg once daily	175 units/kg once daily
Dose adjustment in CKD	CrCl>30 ml/ min: No adjustment required CrCl<30 ml/ min: 1 mg/ kg once daily	CrCl>30ml/min: No adjustment required CrCl<30ml/min: Dose adjust as needed based on anti-Xa level	CrCl>20 ml/ min: No adjustment required CrCl<20 ml/ min: Dose adjust as needed based on anti-Xa level

(Hughes et al., 2014)

tinzaparin 175 units/kg once daily for the treatment of VTE with no signs of accumulation or increased risk of bleeding (Mahe et al., 2007; Pautas, Gouin, Bellot, Andreux, & Siguret, 2002; Siguret et al., 2000). There is limited evidence on the use of tinzaparin in end-stage renal disease, but tinzaparin has the largest molecular weight and the least dependency on renal clearance of all the agents (Table 1). Despite limited clinical trial evidence confirming the safety of its use in VTE treatment in patients with end-stage renal disease (including dialysis), tinzaparin appears to be the agent that is least likely to accumulate in CKD.

### MONITORING

### Anti-Xa Levels

It is evident that information for the use of LMWH in patients with CKD is limited, making monitoring of therapy an important aspect if LMWH is to be used in this patient population. Because LMWH exerts its action through the binding of anti-Xa, a laboratory test assessing anti-Xa factor activity can identify accumulation in a patient. The anti-Xa level can be measured as a peak level, which is drawn four hours after administration of the third dose, or as a trough level taken immediately prior to administration of the fourth dose. The peak anti-Xa target range for treating VTE is 0.5–1.0 units/ml and the trough level should be <0.5 units/ml. It should be noted that this value may change depending on specific laboratory parameters (Hughes et al., 2014).

### **Adverse Events**

Bleeding is the major risk associated with the use of LMWH in patients with CKD. While anti-Xa levels should be closely followed, patients should also be monitored for early clinical signs of bleeding. This is especially important because patients with CKD are at an increased risk of bleeding in general compared to the non-CKD population (Schmid, Fischer, & Wuillemin, 2009). Clinical signs of bleeding may include episodes of epistaxis, hematuria, or melena, but bleeding may occur at any site. It can be difficult to detect in certain situations such as retroperitoneal bleeding, therefore hemoglobin levels should be closely followed to monitor for potential decrease that can signify undetected bleeding (Sanofi Canada, 2014).

### SUMMARY

The use of LMWH in patients with CKD requires caution and careful monitoring due to the risk of accumulation and bleeding. Evidence supporting its use in treating VTE in this patient population is quite limited, and selection and dosing of specific agents requires consideration of the current evidence available, as well as pharmacokinetic properties. Taking into account these factors, tinzaparin is the agent least likely to accumulate in renal failure due to its larger molecular weight, making it less dependent on renal elimination. Regardless of which agent is used, monitoring of anti-Xa levels plays an important role in ensuring that patients are being appropriately anticoagulated and that the risk of accumulation and potential bleeding is minimized.

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### CONTINUING EDUCATION STUDY QUESTIONS

**CONTACT HOUR: 2.0 HRS** 

### Low molecular weight heparin for the treatment of deep vein thrombosis and pulmonary embolism in patients with chronic kidney disease

By Jennifer Ma and Marisa Battistella

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- 1. Which of the following statements is TRUE regarding the treatment of VTE in CKD patients?
  - a) Long-term treatment with LMWH is the treatment of choice in CKD patients.
  - b) Warfarin is contraindicated in CKD patients due to risk of accumulation.
  - c) The use of LMWH in CKD patients is cautioned against due to the renal clearance of these agents.
  - d) New oral anticoagulants are the treatment of choice in CKD patients.
- 2. The mechanism by which LMWH causes anticoagulation is:
  - a) inhibition of coagulation factors Xa and II
  - b) inhibition of coagulation factors X, IX, II, VII
  - c) inhibition of coagulation factor Xa only
  - d) inhibition of coagulation factor II only
- 3. Which of the following statements is TRUE regarding the clearance of LMWH?
  - a) A LMWH with a smaller molecular weight is less dependent on renal clearance.
  - b) A LMWH with a larger molecular weight is more likely to accumulate than LMWH with a smaller molecular weight.
  - c) Renal clearance is directly proportional to the molecular weight of the LMWH.
  - d) A LMWH with a larger molecular weight is less dependent on renal clearance.
- 4. Which of the following is correct in ranking the level of dependency on renal clearance from HIGHEST to LOWEST?

- a) enoxaparin > tinzaparin > dalteparin
- b) enoxaparin > dalteparin > tinzaparin
- c) dalteparin > enoxaparin > tinzaparin
- d) dalteparin > tinzaparin > enoxaparin
- 5. Which of the following statements is FALSE regarding the use of enoxaparin in CKD?
  - a) There is not an increased risk of accumulation or bleeding in CKD patients.
  - b) Enoxaparin has the highest dependency on renal clearance of the LMWH.
  - c) The dose of enoxaparin should be reduced if CrCl <30 ml/min.
  - d) Patients with CrCl <30 ml/ min have been shown to have a higher risk of bleeding when treated with enoxaparin.
- 6. Which of the following statements is FALSE regarding the use of dalteparin in CKD?
  - a) There is no evidence studying the use of dalteparin in treating VTE in CKD patients.
  - b) Dalteparin has the lowest dependency on renal clearance of the LMWH and is the least likely to accumulate.
  - c) Dalteparin has been safely used as thromboprophylaxis in patients with a CrCl <30 ml/min. 10. If patients with CKD are initiated
  - d) There are specific dose adjustment recommendations for patients with CKD.
- 7. Which of the following statements is FALSE regarding the use of tinzaparin in CKD?
  - a) Elderly patients with a CrCl 20-50 ml/min have been safely treated with tinzaparin.

- b) Tinzaparin is the least likely to accumulate in renal failure due to its larger molecular weight.
- c) Tinzaparin has the highest dependency on renal elimination and is most likely to accumulate in renal failure.
- d) There are no specific dose adjustment recommendations for patients with CKD.
- 8. Which of the following dose recommendations are TRUE?
  - a) Enoxaparin should be dosereduced to 1 mg/kg once daily if a patient's CrCl is <30 ml/min.
  - b) Dalteparin should be dosereduced to 100 units/kg once daily if a patient's CrCl is <30 ml/min.
  - c) Tinzaparin should be dosereduced based on anti-Xa levels if a patient's CrCl is <50 ml/min.
  - d) Enoxaparin does not require dose adjustment in CKD.
- 9. In general, the correct peak and trough anti-Xa target is:
  - a) peak: 0.5–1.0 units/ml; trough: <1.0 units/ml
  - b) peak: 0.5–1.0 units/ml; trough: <0.5 units/ml
  - c) peak: 1.0–1.5 units/ml; trough: <1.0 units/ml
  - d) peak: 1.0–1.5 units/ml; trough: <0.5 units/ml
- on LMWH, the MOST important signs and symptoms to monitor for are:
  - a) nausea, vomiting, and diarrhea
  - b) melena, hematuria, epistaxis, drops in hemoglobin
  - c) increased ALT, ALP, AST, and bilirubin
  - d) nephrotoxicity and ototoxicity

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### CONTINUING EDUCATION STUDY ANSWER FORM

CE: 2.0 HRS CONTINUING EDUCATION

### Low molecular weight heparin for the treatment of deep vein thrombosis and pulmonary embolism in patients with chronic kidney disease

Volume 26, Number 3

By Jennifer Ma and Marisa Battistella

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7.	а	b	с	d
8.	а	b	с	d
9.	а	b	с	d
10.	а	b	с	d

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	Strongly	disagre	e S	Strongly	agree
1. The offering met the stated objectives.	1	2	3	4	5
2. The content was related to the objectives.	1	2	3	4	5
3. This study format was effective for the content	. 1	2	3	4	5
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# Advance care planning in advanced chronic kidney disease: Practical communication tips for clinicians

By Betty Ann Wasylynuk and Sara N. Davison

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### ABSTRACT

Patients with advanced chronic kidney disease are often faced with sudden, serious health events that may render them unable to make healthcare decisions. Advance care planning (ACP) ensures that, through shared decision-making, a plan is in place that outlines clearly the patient's healthcare wishes, including end-of-life care wishes, should the patient be unable to direct their care. ACP done early and throughout the illness trajectory helps patients cope with their illness and improves end-of-life outcomes. As a critical component of patient-centred care, ACP should be embedded into routine kidney care. This is not routinely happening, as many clinicians feel they lack the skills and confidence to have ACP conversations with their patients. The purpose of this article is to provide kidney care teams with ACP communication tips aimed at fostering competence and confidence so that clinicians can embed ACP into routine clinical practice.

The illness trajectory for patients with advanced chronic kidney disease (CKD) is unpredictable. Patients are frequently faced with sudden, serious health events that may render them incapable of making their own healthcare decisions (Wasylynuk & Davison, 2015). These health events may precipitate the patient's end-of-life journey. When goals for care have not been established, patients often experience unnecessary hospitalizations, unwanted invasive treatments, a prolonged dying process and, ultimately, the type of death they would not have wanted (Davison, 2012).

Advance care planning (ACP) is about conversations with patients and their family and shared decision-making to ensure a care plan is in place that outlines clearly the patient's healthcare wishes and end-of-life care preferences should they be unable to direct their own care. ACP conversations, when done early and throughout the patient's illness, not only improve end-of-life outcomes, but also help patients adjust to their illness (Bernacki & Block, 2014). For these reasons, ACP is seen

#### **ABOUT THE AUTHORS**

Betty Ann Wasylynuk, BScN, RN, Palliative Care Clinical Nurse Educator, Northern Alberta Renal Program (NARP), Alberta Health Services, Edmonton, AB

Sara N. Davison, MD, MHSc (Bioethics), FRCP(C), Professor, Bioethicist, and Health Outcomes Researcher, Faculty of Medicine and Dentistry, University of Alberta, Edmonton, AB

**Address for correspondence:** Betty Ann Wasylynuk, Aberhart Centre, Room 7121, 11402 University Avenue, Edmonton, AB T6G 2J3.

Tel: (780) 407-1163, fax: (780) 407-8220, email: bettyann.wasylynuk@albertahealthservices.ca as a critical component of patient-centred care. Sadly, ACP has not yet been integrated into routine kidney care. Many clinicians feel they lack the skills and confidence to have ACP conversations with their patients (Ceccarelli, Castner, & Haras, 2008; Davison, Jhangri, Holley, & Moss, 2006; Wasylynuk & Davison, 2015). ACP requires effective communication skills, which can be learned and practised (Schell & Arnold, 2012; Moore, 2005). The purpose of this article is to foster competence and confidence of kidney care teams so they can start embedding ACP into routine clinical practice. This will be achieved by providing practical communication strategies, highlighting issues to consider prior to having ACP conversations, and exploring the key elements of ACP conversations.

### COMMUNICATION STRATEGIES TO ENHANCE COMMUNICATION SKILLS

ACP can be challenging and emotional. Effective communication makes ACP and end-of-life conversations less daunting and more rewarding for both the patient and the clinician (Beaven, Fowler, & Russell, 2011). Effective communication is important in any patient-clinician relationship, but becomes even more essential when engaging in conversations where patients are required to disclose and discuss personal values, beliefs, and fears (Swota, 2009). Non-verbal and verbal communication strategies are vehicles for effective communication and help build trust and a positive rapport, which are the foundation for a healthy patient-clinician relationship (Moore, 2005; Swota, 2009).

Non-verbal communication includes body language, behaviours, and the environment, and is as important as spoken words in conveying our compassion, concern, and interest (Moore, 2005). Having strong non-verbal communication skills is the initial step in building rapport with patients (Moore, 2005). Verbal communication strategies focus on how we use our words to develop a common understanding and encourage fruitful dialogue between people. Tables 1 and 2 outline non-verbal and verbal communications strategies, respectively.

### SPECIAL CONSIDERATIONS BEFORE ACP CONVERSATIONS

### **Understand the Purpose of the Conversation**

It is important that clinicians understand that ACP conversations aim to assist patients and their family with: (i) understanding the patient's current health condition; (ii) understanding their prognosis; (iii) understanding treatment options; (iv) weighing the benefits and burdens of treatment options and assessing how they align with their values, goals and beliefs for living well; (v) naming an appropriate substitute decision-maker (SDM) who will speak on the patient's behalf, if required; and (vi) creating an advance

#### Table 1: Non-verbal Communication Strategies

Nonverbal Strategies	Comments
<ul> <li>Create an appropriate environment:</li> <li>Ensure privacy</li> <li>Prevent interruptions (including silencing call bells, electronic devices)</li> <li>Ensure adequate time</li> <li>Remove physical barriers (e.g. tables) between the clinician and patient</li> </ul>	This helps the patient feel safe and comfortable.
<ul> <li>Maintain a relaxed, unhurried, and open posture:</li> <li>Sit down either beside or facing the patient at eye level at distance that is comfortable for the patient (about 1 metre for most patients)</li> <li>Do not fidget or multi-task.</li> <li>Place your hands on your lap or on the arms of the chair (an open posture).</li> </ul>	Sitting conveys the clinician's undivided attention. Eye level shows that what the patient is saying is important and that the clinician is listening. Comfortable distance conveys a sense of caring and respect for the patient's personal space. This conveys the clinician's readiness to listen. An open posture invites conversation, whereas a closed posture (e.g., crossing arms across the chest) demonstrates defensiveness or cutting oneself off from the conversation.
Make appropriate eye contact	This denotes emotional connection and helps patients engage. Watch for cues suggesting a patient is uncomfortable with eye contact (e.g., gazing away).
Use appropriate touch	When appropriate, gently touch the patient's hand, arm or shoulder. Touch demonstrates empathy. Watch for cues suggesting a patient is uncomfortable with touch (e.g., withdrawing arm/hand). If a patient begins to cry, move closer to them, offer a tissue and gently touch them (if they are comfortable with closer distance and touch).
Active listening: • Lean in towards the patient • Nod • Say hmmm or uh-huh	This demonstrates that the clinician is engaged and cares what the patient is saying.
Listen without interrupting: • Be comfortable with silence	This allows the patient to respond at their pace.

(CHPCA, 2008; Epner & Baile, 2014; Moore, 2005; Moore, 2007; Pearce & Ridley, 2016; State of Victoria, Department of Health, 2012.)

care plan that will document the patient's wishes. It is not necessary that all issues be addressed in one clinical encounter, but rather that they be addressed according to relevancy and patient readiness in subsequent visits.

#### **Consider the Appropriate Timing of the Conversation**

Ideally, ACP should be integrated into routine kidney care early and readdressed throughout the patient's illness. This helps in the following: (i) to normalize the process; (ii) to afford patients the time to think, reflect, and make well informed choices for future care; and (iii) to ensure that care plans remain aligned with patients' preferences and prognosis, as their health state declines (Bradshaw, Smith, & Sinclair, 2016). This often proves challenging, as patients may feel that ACP is not yet relevant early in their disease. However, sudden illness or complications can occur without warning. Integrating screening tools into routine clinical practice, such as the Surprise Question (Would you be surprised if the patient died in the next 12 months?), can help ensure that patients most likely to benefit from ACP are approached in a timely manner (Davison, 2011). There are also triggers that help flag when ACP conversations should be reviewed or introduced if not yet initiated. These include a new life-limiting diagnosis, deterioration in health status, signs of cognitive impairment, or a change in the patient's personal circumstances (e.g., loss of a support system, change in living condition) (Davison & Torgunrud, 2007; Mullick, Martin, & Sallnow, 2013).

### Patient and Family Readiness to Have ACP Conversations

Patient participation is required for successful ACP and these conversations should be tailored to the readiness of the individual (Davison & Torgunrud, 2007). Engaging in ACP is a health behaviour and behaviour change theories such as the trans-theoretical model (TTM) or "Stages of Change" model provide a useful framework for assessing patient readiness to engage in ACP (Fried, Bullock, Iannone, & O'Leary, 2009). Patients go through the stages of pre-contemplation (no intention of engaging in ACP in the near future), to contemplation (thinking about engaging in the near future), to preparation (commitment to engage in ACP soon), to action (a recent ACP behaviour), and maintenance (ongoing behaviour change). This framework takes into account an individual's weighing of the pros and cons of engaging in ACP and assesses their attitudes about barriers to and facilitators of behaviour change. Religious beliefs and medical misconceptions can act as barriers to ACP participation (Fried et al., 2009; Fried et al., 2012). For example, cultural, spiritual, and religious beliefs and variances around the concepts of autonomy, decision-making authority, and communicating prognosis and views around end-of-life care, may influence attitudes towards ACP (Davison, Holley, & Seymour, 2010).

Clinicians should understand the patient's cognitive and emotional state. A patient who is cognitively impaired or who is depressed or extremely anxious may have limited ability to

#### Table 2: Verbal Communication Strategies

Verbal Strategies	Comments
Speak slowly and clearly using simple everyday language. Use short words and sentences in a language that the patient understands. Use a friendly and comforting tone.	This helps the patient understand and digest what has been said/asked. Most patients understand information presented at a Grade 6 to 8 level. This invites discussion.
Speak honestly and in a straightforward manner.	Patients value open and honest information. This fosters trust and respect.
Avoid medical jargon and euphemisms.	Medical jargon causes confusion and distances the patient from the clinician. If medical jargon is used, follow with a layman's description and ask the patient if they understand. Euphemisms cause confusion, as they are often misinterpreted.
Pause often.	This allows the patient time to reflect on what has been said, to ask questions, or to make comments (a count of four seconds is a suggestion).
Use open-ended questions.	This elicits responses that are often descriptive and elaborative, allowing for a better understanding of the patient/family perspective. They provide opportunities from which to draw further questions.
Respond to emotion by verbalizing empathy.	This conveys respect and compassion. "I can't imagine how difficult that must have been for you and your family." "I admire your willpower to fight this."
Explore the meaning of ambiguous words and phrases.	"I don't want to be a vegetable." Ask: "What does being a vegetable mean to you?" or "What does being a vegetable look like to you?" "I don't want to be a burden." Ask: "What do you mean by being a burden?" "I want to die with dignity." Ask: "What does dying with dignity look like to you?" "I don't want heroics." Ask: "What do you mean by heroics?"
Use screening questions.	This allows the patient to add additional information before going on to the next question. "Is there something else you are afraid of?"
Paraphrase what you have heard.	This shows that the clinician was listening and also provides an opportunity for the patient to clarify any misunderstanding and/or provide further information. "So, what it sounds like you are saying is is that correct?"
Check for understanding.	Ensure the patient understands what has been said. "Now, hearing the responsibilities of a substitute decision-maker, who would you trust to take on this role and why?"
Summarize before going onto a new topic and at the end of the conversation.	Ensures a mutual understanding of what has been discussed.

(Balaban, 2000; Beaven et al., 2011; Bernacki & Block, 2014; CHPCA, 2008; Epner & Baile, 2014; Moore, 2005; Moore, 2007; Pearce & Ridley, 2016; Respecting Choices, 2007; State of Victoria, Department of Health, 2012; von Gunten, Ferris, & Emanuel, 2000.)

participate meaningfully in ACP (Davison, 2012). This reinforces the importance of integrating ACP into routine clinical practice early in the patient's illness, prior to a crisis, which may render them unable to make informed choices for care. Clinicians should address reversible factors, including any misconceptions the patient may have towards ACP. The evidence suggests that a patient is much more likely to engage actively in ACP when he/she understands the personal relevance and perceived benefit (Davison & Torgunrud, 2007; Simon, Porterfield, Bouchal, & Heyland, 2015).

A patient's willingness to participate in ACP may change over time. For those not yet ready to engage in conversations, it is important that the invitation remains open (Mullick, Martin, & Sallnow, 2013). Some patients may express their readiness by openly stating so, while others may do so through indirect verbal cues using phrases such as, "I don't know if this is all worth it to me anymore," "I am getting tired of this," "I don't want to be a burden," "What happens if I stop dialysis?" It is vital that such cues be explored with the goal of understanding the patient's concerns and looking for remedial solutions.

#### **Clinician Readiness to Have ACP Conversations**

Clinicians should be encouraged to explore their personal and professional comfort with and willingness to engage in ACP before engaging in conversations with patients and families (CHPCA, 2008). As with patients, clinicians' religious, spiritual, or cultural beliefs may influence their attitude towards ACP. Having an awareness of individual differences from that of the patient is important to create a respectful and non-biased dialogue (Wasylynuk & Davison, 2016). If the clinician's views and values conflict with that of the patient such that they feel unable to negotiate a balanced and respectful conversation, the patient should be referred to another clinician (CHPCA, 2008).

### **KEY ELEMENTS OF THE ACP CONVERSATION**

There are several key elements to ACP conversations. These are outlined in Table 3. It is not necessary that all elements be addressed in a single conversation, but rather that over time both the patient and clinician gain a full understanding of the patient's beliefs, values and overall goals for care. This is often aided by exploring past healthcare

Table 3: Key	Elements in ACF	Conversations
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Key Element	Goal(s)	Sample Questions
Initiate the conversation	<ul> <li>Introduce ACP and normalize the topic.</li> <li>Explore patient's understanding of ACP.</li> <li>Assess patient's readiness to participate in ACP by asking them permission to discuss ACP.</li> </ul>	"One thing I discuss with all my patients is advance care planning. Do you know what this is?" "I would like to spend a few minutes talking to you about how you see your health at the moment and what you would want for medical treatment should you suddenly become too sick to tell us. Would this be okay?" "None of us knows what tomorrow will bring. A sudden illness or injury may leave you unable to make healthcare decisions. Healthcare professionals would need to turn to your family to make decisions on your behalf. However, without having prior discussions with your family, they may not know what you would want for medical care. This can cause them stress and anxiety, and a good chance that you will not get the care that you would want had you been able to speak for yourself."
Explore current health condition	Assess what the patient knows about their kidney disease, its progression, and their treatment options (dialysis, conservative kidney management, dialysis withdrawal)	"What do you understand about your kidney disease?" "What bothers you most about your kidney disease?" "How do you see your health at the moment?" "What do you know about treatment options?" "What do you hope to achieve with dialysis?" "Where do you see things going with your illness?" "How much information about what is likely to happen down the road because of your illness would you like from me?"
Explore values, goals, and beliefs on living well	Understand the patient's values, beliefs, fears, and goals of care	"What gives your life purpose or meaning?" "What things must you be able to do to have quality of life? If you couldn't do these things, how would you feel?" "Are there circumstances that would make your life not worth living?" "What are your most important goals if your health condition worsens?" "Is it more important for you to live as long as possible, even if this means suffering, or to live shorter without suffering?" "What are your biggest fears or worries about the future with your health?" "Are there religious, spiritual or cultural beliefs that are important to you? How do these beliefs influence your healthcare wishes?"
Explore past health experiences	Understand how past experiences influence healthcare decision-making, explore what defines a good death for the patient	"Tell me about the last time you were in the hospital." "What did that time mean to you?" "If this were to happen to you again, what would you like to have happen differently (same) the next time?" "Have you had anyone close to you who was seriously ill and died?" "How would you want to be cared for in this situation?" "What don't you want to have happen to you in this situation?" "Have you thought about what kinds of treatment you would (would not) want if you were unable to speak for yourself?" "Most people have thought about the way they would like to die. What are your thoughts on this?"
Clarify goals for life-sustaining treatments	<ul> <li>Discuss hypothetical scenarios including treatment options and potential health outcomes.</li> <li>Assess that the patient's wishes for life-sustaining treatment are consistent with their goals for living and dying well.</li> <li>Discuss conditions in which the patient would want life-sustaining treatment stopped.</li> </ul>	<ul> <li>"Say, for example, you have a serious health event that has left you unable to speak and your substitute decision-maker needs to make an immediate medical decision about using life-sustaining treatments. Doctors believe you have a good chance of living through this event, but expect you will:</li> <li>1. never be able to care ( walk, dress, bathe, toilet) for yourself again once you recover</li> <li>2. have permanent and severe brain damage (you are able to open your eyes, but unable to speak or understand).</li> <li>3. be in a permanent coma from which you are not expected to wake up or recover, and you will have brain damage."</li> <li>"Would you want life-sustaining treatments to prolong and preserve your life, because for you it is the quantity of life that matters most OR would you want to allow a natural death to occur because for you comfort and the quality of your life means the most?"</li> <li>"If your heart suddenly stops beating would you want CPR attempted?"</li> </ul>

continued on page 24...

ldentify a substitute decision-maker (SDM)	Ensure SDM is appropriate, understands patient's wishes, is willing to act as SDM, and commits to honouring the patient's wishes	"If you were unable to make your own healthcare decisions, who knows your healthcare wishes the best and who would you trust to speak on your behalf?" "Is this person tough enough to make these important decisions under a stressful time?" "Have you spoken to this person about you wanting them to be your substitute decision-maker?" "Have you discussed your wishes with them?"
Encourage communication with others	Ensure patient communicates their wishes to their family, loved ones, and all members of their healthcare team	"How much does your family know about your wishes?" "I know this may not be an easy conversation to have with your family, but involving them now helps them prepare and cope. It also helps them know your wishes so they can support your substitute decision-maker when carrying out your wishes. This can help avoid family conflict." "What have you told your doctor or the healthcare team?" "It would be beneficial for your doctor and the healthcare team to know your healthcare wishes so you are given the care you want should you be unable to tell us."
Summarize and close the conversation	<ul> <li>Summarize and ensure mutual understanding</li> <li>Document the conversation and ensure treatment preferences are translated into an advance care plan</li> <li>Encourage patient to complete an advance directive</li> </ul>	

(Holley, 2007; Koncicki & Schell, 2016; Moore, 2005; Moore, 2007; Pearce & Ridley, 2016; Respecting Choices, 2007; Schell, Green, Tulsky & Arnold, 2013; State of Victoria, Department of Health, 2012; Wasylynuk & Davison, 2016.)

experiences. It is only through this exploration and understanding that the clinician will be able to align treatment options and end-of-life care with the patient's personal goals for living and dying well. In routine clinical practice, it is not uncommon for these conversations to build upon each other in subsequent visits.

Exploring the patient's understanding of their health provides the opportunity to address knowledge gaps and allows the clinician to understand illness from the patient's perspective. This is central to understanding their preferences for care (Gallagher, 2008). Inquiring about expectations allows the opportunity to explore unrealistic expectations or misconceptions (Davison & Torgunrud, 2007). Exploring the patient's values, goals, and beliefs on living well allows both patients and clinicians to reflect upon what matters most to an individual, such as what health conditions or outcomes are not acceptable and what the patient's overall focus is (i.e., quality or quantity of life). Exploring past health experiences of the patient and/or others close to the patient often give patients insight into choices for their future healthcare, including end-of-life care.

Using the above information while discussing hypothetical disease specific scenarios can help patients clarify goals for life-sustaining treatments. Patients are often poorly informed of anticipated benefits of treatments such as cardiopulmonary resuscitation (CPR) (e.g., the six-month survival rate following CPR is approximately 3% for dialysis patients with a high risk for significant and sustained physical and/or cognitive disability) (Moss, Holley, & Upton, 1992). Following the approach in Table 3, patients should be well positioned to reflect on whether various treatment options align with their goals for living and dying well when discussing disease specific scenarios.

Ideally, the SDM should be present for ACP conversations to prepare them to carry out the patient's wishes (Respecting Choices, 2007). Patients must understand the importance of communicating their healthcare wishes with their family, loved ones, and their SDM. This helps to ensure that family and loved ones support the SDM when carrying out the patient's wishes, avoiding conflict around end-of-life decision-making (Davison, 2012). For patients who have difficulty talking to their family/loved ones, the clinician may need to host a family/group meeting. Equally important, patients are encouraged to communicate their healthcare wishes and share their advance care plan with their healthcare providers to ensure their healthcare wishes are transparent throughout the healthcare system. Finally, because healthcare wishes can change over time, patients are encouraged to have ongoing discussions with their SDM, family/loved ones and their healthcare team. Patients should be made aware of the importance of keeping their advance care plan up-to-date.

### SUMMARY

ACP is a critical component of quality kidney care that can improve both the lives and deaths of patients with advanced CKD (Davison, 2006). Unfortunately, ACP has not yet been embedded into routine kidney care, primarily because members of the kidney care team often feel they lack the skills and confidence to have these conversations. Effective ACP communication can be learned and practised. By providing clinicians with strategies to enhance their non-verbal and verbal communications skills and a framework for facilitating these conversations, care teams can begin to acquire competence,

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comfort and, finally, confidence in conducting ACP within routine clinical practice.

"With practice comes competence. With competence comes comfort. With comfort comes confidence." (Anonymous)

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