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Difficult and frustrating? Caring for those with chronic and complex conditions

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Difficult and frustrating? Caring for those with chronic and complex conditions

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Caring for people with chronic and complex health needs has become an ever-larger part of everyday nursing. The World Health Organization has identified common and preventable risk factors that are the primary cause of chronic illness worldwide—hypertension, tobacco use, hyperglycaemia, physical inactivity, and overweight or obesity. Nurses now need an expanded range of skills and expertise that will enable them to work effectively with people whose chronic and frequently complex health issues may be seen as difficult and challenging.

This article invites you to think about your experiences of caring for people with chronic and complex conditions. Before you read any further, take a moment to think about your response to some initial questions. How would you describe your attempts to work with people with chronic and complex health needs? Do you find yourself struggling to understand when your patient doesn't appear to be following professional health advice? What do you hear your colleagues say about chronic illness?

Differing perspectives

To prevent the conditions associated with chronic disease risk factors requires individuals to take personal responsibility for their health. Herein lies the challenge for nurses, specifically, how do you work with people who do not seem to you to be taking responsibility for their health? This is noted as a widespread nursing problem. It's not uncommon to hear expressions of frustration, at times harsh judgments, and descriptions such as difficult, noncompliant, demanding, and uncooperative applied to patients with chronic and complex conditions. Have you ever found yourself making statements such as, "I've told him what he needs to do: last time he came I gave him the handouts again," "It's just so frustrating to have him come back again and nothing has changed," and "I don't know what I need to do to make him take responsibility for his health."

Look closely at the language in the last paragraph; the voice of frustration speaks loudly in conjunction with the voice of professional authority: "I've told him what he needs to do." Now, look just as closely at the experience of chronic disease sufferers—what is their reality? Many people with chronic conditions are attempting to manage two or more conditions while retaining a "normal" life, which may or may not include responsibility for the care of others. The advice, recommendations, and sometimes the directives offered to manage chronic illness may be perceived as being in direct conflict with living a normal life or with the person's responsibilities as a parent, spouse, or a caregiver of aging parents. The voice of the person experiencing life with one or more chronic conditions talks of the importance of living a normal life and of the way that trying to manage chronic illness reduces the time available for living.

Thus nurses may find they are working at cross-purposes with a focus and goals that are not closely aligned with those living with chronic illness. Actively supporting and encouraging self-management has been demonstrated to be beneficial; however, taking an authoritarian or "compliance-based" approach to self-management has been shown to be singularly unhelpful. At this point, it's helpful to think about your own assumptions and biases. What are your expectations of the person with the chronic condition? How do you define your role in this situation? Think back to a time when you were struggling with a person who did not seem to you to be actively engaged in improving his or her health. Can you identify the emotions that you were experiencing at the time? Do words such as aggravated, dismayed, exasperated, frustrated, impatient, irritated, or irked describe what you were feeling? Are you able to identify the judgments that gave rise to these emotions? How do you feel that this person's apparent lack of effort reflects upon you? Or perhaps you found yourself feeling powerless or pessimistic in the face of this person's apparent unwillingness or potential to change his or her behavior. Labels such as difficult, pointless, or noncompliant may have appeared in thinking about the person.

Self-recognition

While responding with frankness to these types of questions may be uncomfortable, recognizing your own emotional responses and judgments is the first step required to enable you to move from a stance of professional authority to one of enhanced compassion and support. At times, that cloak of professionalism may separate you from the universality of human experience. When the focus of nursing care is directed toward a specific chronic illness, awareness of the challenges of living with chronic illness may be lost. Recognition of the complexity of the person's life,

and his or her struggle to maintain a balanced life likewise disappears. A focus on disease or illness shifts attention away from holistic, patient-centered care.

Take a moment to think about the needs that you have. Despite personal differences, needs for connection, honesty, peace, autonomy, well-being, and meaning are common to all. Recognizing the commonality of these needs for both you and the person with a chronic illness reveals the need for compassionate care; care that is collaborative, respectful, and which enables the maintenance of autonomy and independence. To really hear what is needed requires you to recognize the impact of the illness upon the person's emotional state. However, despite your best efforts, your attempts to listen may be met with expressions of frustration and indeed anger, especially when the person's expectations of care are not being met. If in turn you then respond from a place of frustration or hurt, the scene is set for increasingly difficulty encounters. How you negotiate the difficult encounters will have a significant impact upon your future efforts to effectively engage the person in self-management.

Competencies and tools

Nursing people with chronic and complex needs requires the development of higher-level psychological and interpersonal competencies. This is challenging work that calls for a fine balance between compassion and empathy and your ability to maintain your role as a skilled and effective nurse. Losing your balance may place you at risk of burnout or indifference.

Many tools are available to assist nurses seeking to build their capacity to work with people who provoke challenging emotions and judgments. Reflective practice and self-awareness are important in helping you to identify the judgments and emotional responses that will adversely affect your capacity to provide effective care. Regular engagement in individual or group clinical supervision can provide a safe space in which to explore the challenges of nursing those with chronic and complex conditions. This also can be a space where you strengthen your interpersonal skills and confidence to keep the person at the center of your nursing care.

The practice of mindfulness or focused awareness has demonstrated capacity to enable you to develop and sustain a therapeutic relationship and to see the person in a holistic way. Importantly, there is growing evidence that regular mindfulness practice can enhance clinician well-being and reduce burnout. Maintenance of your own physical fitness and overall health is a proven buffer to challenging times. Treating yourself with compassion and kindness will equip you to extend understanding and compassion to patients in your care who may at times frustrate or challenge you.

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