Expert Consensus Statement:
Nursing decision-making for subcutaneous medication preparation and administration in home-based palliative care

Preamble

The BC Centre for Palliative Care (BCCPC) is a provincial organization funded by the BC Ministry of Health established to work with partners in the health system and community to accelerate the spread of innovations and best practices in palliative care.

Introduction

Many people living with serious illness are cared for at home as their illness progresses. Family caregivers[i] play an essential role. When people with life-limiting illness are prescribed subcutaneous medications and are receiving nursing care at home, there are nursing decisions to be made related to the tasks involved in the medications' preparation and administration.

In Canada, it is common for home-care nurses[ii] to pre-draw and label subcutaneous medications for family caregivers to administer to people with advanced progressive life-limiting illness at home. However, there is limited evidence to base guidelines for this nursing practice and significant variability in existing guidelines. Some standards specify that medication should only remain in syringes for a short period of time before administration,[1-3] whereas others guide nurses to consider several related factors in the decision.[4,5] Application of standards designed for facility-based care settings or for pharmacy compounding of parenteral medications can profoundly impact the ability for subcutaneous medications for palliative care to be provided within a person's home. An expert team of nurses, prescribers, pharmacists and family members with lived experience created the following consensus statement to address this reference gap. **The expert consensus statement received 100% consensus** (n=20).

[i] Family is used to describe anybody close to a person who they consider family, including close friends.

[ii] Home-care nurse is used to refer to 'a regulated nurse providing care in the person's home'. The nurse may be termed by different names, such as community health nurses and home health nurse.

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Without injectable subcutaneous medications administered at home, many people with advanced life-limiting illness who wish to stay at home would suffer poorly managed symptoms and be unable to die comfortably at home. Home-care nurses are critical to ensuring safe, effective preparation and administration of subcutaneous medications in these situations.

After a subcutaneous medication has been prescribed and the person has the injectable medication vials in their home, the home-care nurse, when involved, must determine what aspects of subcutaneous medication preparation and administration are appropriate for the person and their family caregiver. At each visit, the nurse must determine who completes which task: the person, the family caregiver, or the nurse. The tasks for which decisions are required include whether the medication is prepared in advance (pre-drawn), and whether the nurse or family caregiver does this preparation. The nurse also then needs to provide the applicable teaching and direction for preparation and/or administration, and disposal.

An expert panel of clinicians (nurses, prescribers and pharmacists), informed by the perspectives of family members with lived experience confirmed 14 factors relevant to nursing decision-making regarding the preparation and administration of subcutaneous medications for people receiving palliative care at home (Appendix). The priority of each factor in the decision is influenced by the specific situation for the person with life-limiting illness.

This is a complex decision,[iii] made by a regulated nursing professional who can weigh multiple considerations in the unique context of the person, their family, their home, and community environment.[6] These decisions are individual to the context of the situation and must be revisited by the nurse at each home visit, as change is expected with people requiring palliative care.

Nurses must consider all 14 factors when making decisions related to subcutaneous medication preparation and administration in the home. The decision should not only be directed by a pre-determined time limit by which a pre-drawn syringe must be administered, but all the factors in relation to the situation and the risks and benefits of each.

[iii] The components of nursing critical thinking required to determine the best approach in complex situations are described in Gillespie's 'Situated Clinical Decision-making Framework'.

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From the perspective of all groups in the expert team, the most important factors in any palliative care situation regarding preparation and administration of subcutaneous medications at home are how the person's goals of care will be affected by the decision, and the family caregiver's willingness. Nurses consider family caregiver cognitive capabilities and safety in the home as the next most important factors in decision-making. Although considered important factors, nurses ranked medication sterility and stability the lowest.

While both the group of nurses and the group of prescribers and pharmacists confirmed the relevance and importance of the same 14 factors, there were differences between the two groups in the relative importance of the factors; confirming the different perspectives and roles for nurses as compared to prescribers and pharmacists.

Subcutaneous medication prepared and administered at home is given with a risk of less stability, and therefore less potency, and a risk of non-sterility compared to medication delivered at health-care facilities, due to differences in how medication is prepared and stored. These risks are seen as acceptable in the context of delivering medications to persons with life-limiting illness receiving palliative care at home, given a likelihood of greater symptom burden and/or an inability to receive care at home if these medications are not available.

Shared decision-making between the home-care nurse, person requiring the medication and family caregiver/s is crucial. For the person and their family, administration of subcutaneous medications is only one aspect in their overall palliative journey.

Supporting nurses, people with life-limiting illness and their families requires policy and practice standards that recognize the specifics of these situations. This includes: the unique role of the home-care nurse; the specific context of palliative home-based care; evidence specific to the subcutaneous rather than intravenous route; and most importantly, that this is shared decision-making that supports the person and their goals in their last days, weeks, and months of life.

Implications

Health systems:

- Ensure the perspectives of people with lived experience (the target population) inform policy development relating to the preparation and administration of subcutaneous medication for those with life-limiting illness at home.
- Ensure policies/guidelines recognize the professional scope of nurses to use their clinical knowledge and assessment skills to make the decisions related to preparation and administration of subcutaneous medication for people with life-limiting illness at home and the clinical scenario.
- Review current policy being applied based only on sterility and stability concerns. Using only these factors for the complex decision making severely limits time periods for pre-drawn subcutaneous medications for people with palliative needs at home.
- Ensure references such as Care Beyond Cure: Management of pain & other symptoms (2009)[7] about stability and conditions to maintain potency for subcutaneous medications are maintained and widely accessible for home-care nurses.

Practice:

- The list of decision-making factors should NOT be used as a checklist. Factors are considerations in nursing decision-making, NOT requirements.
- Create references for creative problem solving to mitigate factors to enable willing family caregivers to be involved with subcutaneous medication preparation and administration, when appropriate.
- Create practice resources to better inform family caregivers about what is possible, to enable and encourage their involvement to the degree they wish and are capable of, exploring their wishes and worries as well as the risks and benefits to ensure informed decision-making.

People living with life-limiting illness and Family Caregivers:

- Participate in shared decision-making related to subcutaneous medication preparation and administration.
- Understand the tasks required with subcutaneous medications and be informed of various ways family caregivers can be involved in preparing and administering subcutaneous medications to the person with life-limiting illness in the home.
- Seek information, ask questions about what can be expected, what is possible, specifically how they could be supported, sharing family caregiver wishes and worries.

Education:

- Teach novice nurses about the relevant factors in decision-making and the importance of using the situational decision-making process.
- Develop education materials to support nurses to learn about decision-making in the palliative care context including case scenarios, including mitigation strategies for some factors and aspects.
- Develop education materials to support family caregivers in shared decision-making, not only in performing the task.

Research:

- Further research is needed about stability and sterility of pre-drawn syringes prepared in the home to build on the small-scale studies from Australia about sterility.[8]
- This work would benefit from further review by a broader group of people with lived experience and further study to better understand their perspectives about risks and benefits, including any cultural considerations.

Evidence Base

Consensus process

The BC Centre for Palliative Care (BCCPC) convened a provincial reference group of 7 experts in palliative home-care nursing practice (5 nurses, 1 pharmacist, 1 nurse practitioner) to advise the project team. The reference group endorsed using a modified Delphi consensus process.

Palliative care clinicians were identified as experts if they were experienced in palliative home-care and working in palliative care leadership and consultation roles. They were then invited to be part of the consensus process. The consensus panel comprised of two sub-groups who completed the surveys:

- 14 nurse experts in home-care palliative practice from all 5 regional health authorities in BC.
- 5 clinician experts in home-care palliative practice: 2 pharmacists, 2 palliative physicians and a nurse practitioner.

Two people with lived experience of being family members giving medications in a syringe to a person with palliative needs at home were sought and identified through Health Quality BC's Patient Voices Network. The family members with lived experience met with the project team after each survey round, to review survey results and provide their perspectives. Their caregiver voices and thoughts were considered by the reference group and informed the consensus statement.

The panel determined the relevance of each factor and the related aspects, how important each factor was in decision-making, and considered three separate scenarios when assessing the importance of the factors:

1) A person was losing the ability to swallow in the last hours/days of life.
2) A person with life-limiting illness in the last few months of life had symptoms requiring subcutaneous route medications for effectiveness.
3) A person was at high risk for a catastrophic event such as a terminal bleed and subcutaneous medications were prepared in advance for quick access in case of the event.

A pre-defined 75% was set as the threshold for consensus. During analysis the agreement rates for both groups were analysed separately.

The project team then drafted the consensus statement and this report, with feedback and input from the reference group and people with lived experience. The consensus panel (minus one member who was on leave) and the people with lived experience were invited to complete a third and final survey. They were asking whether they endorsed the consensus statement: all endorsed the consensus statement (13 nurses, 5 other clinician experts, 2 family caregivers).

Factors (see Appendix)

Through a consensus process, an expert panel of clinicians (nurses, prescribers and pharmacists) and family members with lived experience identified 14 factors relevant to nursing decisions about the preparation and administration of subcutaneous medication in the context of palliative care at home. These factors and their corresponding aspects relate to the person, family, home, community, nurse and policies. The list of factors is NOT meant to be used as a checklist to determine if an action can be taken. Many factors can be mitigated by creative approaches taken by the nurse, person and family.

Evidence Base

Though all 14 factors are relevant, the priority of each factor in the decision is influenced by each person with life-limiting illness and their specific situation. However, across all situations, the following factors were rated by all groups as the most important considerations in the decisions, and play a role in avoiding paternalism:

- **Goals of care of the person with life-limiting illness** and how the decision affects these.
- **Family caregivers' willingness** to be involved with subcutaneous medication preparation and administration. This may be the top consideration in some scenarios.

Very important or important factors:

- **Family caregivers' cognitive capability** or ability to understand and follow instructions.
- **Family caregivers' functional capability** in preparing and administering subcutaneous medications for symptom management.
- **Safety in the home,** including an understanding of risks and harms to ensure safety for others in the home and in the community.
- **Person's condition and predicted time frame.**
- **Family caregivers' mental well-being** related to preparing and administering subcutaneous medications for symptom management.
- **Person's environment,** including the home and the broader community.
- **Nurses' availability** to do home visits for symptom management and support.
- **Backup plan for symptom management** in case of a barrier to administer subcutaneous medication(s).
- **Nurses' knowledge, skill, ability, confidence to teach family caregivers** related to subcutaneous medication for palliative symptom management.
- The use of existing **policies and guidelines** for nursing decision-making related to subcutaneous medication preparation and administration by family caregivers.

For the nurses, relevant but the less important factors in nursing decision-making are:

- **Medication stability** – Medication maintaining its intended therapeutic properties such as strength, quality, and purity after being drawn into a syringe.
- **Medication sterility** – Medication free of microbial growth.

Harms related to sterility and stability, while critical for episodic intravenous medications, must be considered differently in the context of palliative care and the subcutaneous route. Risk of systemic infection is significantly lower with subcutaneous delivery. In situations of pre-drawing medications for a person in their last hours or few days of life or for symptom management in case of a potential life-ending event, the risk of systemic infection is of minimal clinical relevance. Harms related to potential reduced medication potency has less impact in situations that can be mitigated with available PRN (as needed) medications. In contrast, lack of access to prepared subcutaneous medications can have significant consequences to the person's suffering and the experiences of family caregivers and close others. Thus, medication sterility and stability are relevant but relatively less important than other factors when nurses are making decisions about preparation and administration of subcutaneous medications in the context of palliative care at home.

Evidence Base

Perspectives of people with lived experience

Family members with lived experience agreed with the relevance of the 14 factors. They agreed that the relative importance of the factors varied depending on the scenario, but that 'patient's goals of care' and 'family caregiver willingness' are consistently the top factors, with 'family caregiver willingness' being more important in some scenarios.

However, they emphasized this is shared decision-making with the person and family, and to avoid paternalism. They also emphasised the importance of family caregivers being provided with guidance to enable them to understand what to expect and how they'll be supported, which in turn influences willingness. The preparation and administration of these medications is just one task, and the person/family-centered care is what is most important. Family caregivers may rate factors differently. For example, the palliative education of nurses was noted as one of the most important factors to people with lived experience.

For a family caregiver at home with subcutaneous medications, nurses are instrumental because they are aware of the complexities inherent in supporting a person in the home. People with lived experience said the nurses are 'living and breathing' with the family caregivers.

Nurses' distinct view

Although nurses, prescribers and pharmacists confirmed the relevance of the same 14 factors, there were differences between the two groups for the relative importance of the factors; confirming the different perspectives and roles for nurses as compared to prescribers and pharmacists.

Both groups agreed all 14 factors were relevant, but the importance ratings and rankings of factors varied. There were variations in the importance ratings for the aspects for 'medication sterility', with infection/inflammation and 'use of aseptic' technique being rated important by nurses but not prescribers and pharmacists, and 'systemic infection' being important for prescribers and pharmacists but not reaching consensus as important for inclusion by nurses. Further, nurses ranked their knowledge and skill and nurse availability relatively low importance, whereas the others ranked these two factors much more important. Our interpretation of this finding is that prescribers and pharmacists depend on nurses to implement the plans with the person and family caregiver, highlighting the essential role of the nurse in these situations. Nurses operate within their own nursing knowledge, skillsets and availability, which may reduce their perception of its importance.

What the nurse must consider in the home while implementing prescribed medications is different than what the prescriber needs to consider. For example, if a nurse is not knowledgeable or available to implement the injectable medication for subcutaneous administration the prescriber may then make a different decision about route of medication or place of care.

Similarly, for 'family caregiver mental well-being' factor, the aspects of 'ability to handle potential stress and anxiety' and 'attitudes and misconceptions' were both strongly rated as very important by nurses but not non-nurses.

Evidence Base

Applicability of NAPRA Standards

In 2015, the National Association of Pharmacy Regulatory Authorities (NAPRA) published Model Standards for Pharmacy Compounding of Non-hazardous Sterile Preparations (NAPRA Standards).[9] According to the NAPRA standards, injectable medications prepared in a non-pharmacy setting are to be used within one hour, or when prepared in a designated segregated pharmacy compounding area they are to be used within 12 hours. These NAPRA standards, when used as the sole reference, severely limit nursing practice and profoundly impact palliative care provision for people and their families at home.

The applicability of these NAPRA standards has been raised by many in the palliative care community including the Canadian Society of Palliative Care Physicians (CSPCP) and the Canadian Hospice Palliative Care Association (CHPCA). To evaluate the appropriateness of these NAPRA Standards for nursing practice related to subcutaneous medication use for people with palliative care needs at home the Appraisal of Guidelines for Research and Evaluation, Global Rating Scale (AGREE GRS 2017)[10] was applied. AGREE GRS is an international standard to direct the development, reporting and quality appraisal of clinical guidelines.

According to AGREE GRS, in assessing clinical validity of a guideline the recommendations must be appropriate for the intended person and setting. The preparation of subcutaneous medications for administration for people with advanced life-limiting illness at home is not described in these NAPRA standards. These pharmacy standards consider preparation of intravenous medications, prepared in a pharmacy, and to be given at home. The intravenous route, intention of treatment, and tolerable risks of these intravenous treatments are not comparable to the context and needs of people at home with palliative needs receiving subcutaneous medication. Second, NAPRA standards target pharmacy professionals who compound sterile preparations. NAPRA states that their standards could also be used by nurses and physicians,[9, p.5] however, it is not evident whether appropriate palliative care stakeholders[iv], other professions nor people with lived experience of life-limiting illness were consulted in the development process.

Applying the AGREE GRS, the NAPRA preparation of parenteral medications is not an appropriate standard to base direction for nursing preparation of subcutaneous medication for people with palliative needs in the home setting.

Environmental scan and literature review

To determine the evidence base for this nursing practice, we conducted a literature search. We identified 27 articles from the United Kingdom, Australia, the United States, and Europe, with no Canadian publication on this topic.[8,11-32] These articles described the practice of nurses pre-drawing medications for family caregivers to administer at home. As nurses are usually not available 24 hours a day to provide care in homes, family caregivers are heavily relied on to provide care and medication management. Notably, small scale studies from Australia found pre-drawn in-home syringes of injectable medications had maintained sterility for weeks of time.[8]

We located grey literature related to the practice of pre-drawing subcutaneous medication for people

[iv] *BCCPC strives to use anti-colonial language in all our work, however this is the term used within AGREE GRS*

Evidence Base

receiving palliative care at home from 3 Canadian provinces (BC, Alberta and New Brunswick).[1-5] College of Registered Nurses of Alberta Guidelines for Medication and Vaccine Injection Safety[3] does not specifically address the context of palliative populations at home but was being used as the reference applied in palliative home care. In BC and New Brunswick, the time before administration of pre-drawn subcutaneous medications in the guidelines ranges from administration within 24 hours to days.

In the absence of other references and consideration of care context, we found that the pharmacy-based NAPRA standards for the preparation of any parenteral medications are being used to direct home-care nursing practice in palliative care and with subcutaneous medication. This environmental scan revealed a tension between organizational policies/guidelines and the reality of the community-based context of nursing practice to meet the needs of palliative people at home.

Summary

Policy and practice standards that recognize the unique role of the home-care nurse and a clear understanding of the specific context of palliative home-based care are required to support nurses in this important practice. Additionally, consideration of evidence specific to the subcutaneous rather than intravenous route is required. Finally, this is shared decision making with the person and family caregiver aimed at supporting people in their last days, weeks, and months of life.

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Abbreviations

BCCPC	BC Centre for Palliative Care
CHPCA	Canadian Hospice Palliative Care Association
CSPCP	Canadian Society of Palliative Care Physicians
NAPRA	National Association of Pharmacy Regulatory Authorities
PRN	as needed

References

1. Vancouver Coastal Health (2017) Subcutaneous Medication Management (Palliative)
2. Extra Mural Program New Brunswick (2020) Medication Administration
3. College of Registered Nurses of Alberta (2018) Guidelines for Medication and Vaccine Injection Safety
4. Island Health (2020) Pre-Drawing Medications for Community Health Services Guideline
5. Interior Health (2022) Pre-drawing Medications for Palliative Care at Home. Palliative Care Guideline
6. M Gillespie, BL Peterson (2009) Helping novice nurses make effective clinical decisions: The situated clinical decision-making framework. Nursing Education Perspectives 30(3) https://journals.lww.com/neponline/abstract/2009/05000/helping_novice_nurses_make_effective_clinical.7.aspx
7. Hospital Pharmacists, Special Interest Group in Palliative Care (2008) Care Beyond Cure: Management of pain & other symptoms. 4th Edition
8. T Soeyland, A Garner, S Vidler, CH Gutierrez, A Foster, J Kitcher (2018) Predrawn prehospital medications are microbiologically safe for up to 48 hours. Emergency Medicine Journal, 35(12), 743-745 https://doi.org/10.1136/emermed-2018-207864
9. National Association of Pharmacy Regulatory Authorities (2015) Model Standards for Pharmacy Compounding of Non-hazardous Sterile Preparations. https://napra.ca/sites/default/files/2017-09/Mdl_Stnds_Pharmacy_Compounding_NonHazardous_Sterile_Preparations_Nov2016_Revised_b.pdf
10. MC Brouwers, ME Kho, GP Browman, JS Burgers, F Cluzeau, G Feder, B Fervers, I Graham, J Grimshaw, SE Hanna (2012) The global rating scale complements the AGREE II in advancing the quality of practice guidelines. J Clin Epidemiol 65(5):526-34 https://doi.org/10.1016/j.jclinepi.2011.10.008
11. B Anderson, D Kralik (2008) Sterility, stability and potency medications administered by carers in home-based palliative care. The Pursuit of Excellence, (51), 1-4 https://search.informit.org/doi/10.3316/informit.051731796016918
12. NC Chi, G Demiris, KC Pike, K Washington, DP Oliver (2018) Pain management concerns from the hospice family caregivers' perspective. American Journal of Hospice & Palliative Medicine, 35(4), 601–611 https://doi.org/10.1177/1049909117729477
13. MK Dees, EC Geijteman, WJ Dekkers, BA Huisman, RS Perez, L van Zuylen, A van de Heide, E Van Leeuwen (2018) Perspectives of patients, close relatives, nurses, and physicians on end-of-life medication management. Palliative & Supportive Care, 16(5), 580-589 https://doi.org/10.1017/s1478951517000761
14. F Fernandez-Campos, M Mallandrich, AC Calpena, A Ayestaran, C Lacasa (2013) Stability studies of binary and ternary mixtures containing morphine, midazolam, levomepromazine and hyoscine butylbromide for parenteral administration. Journal of Pharmacy & Pharmacology, 65, 379-89 https://dx.doi.org/10.1111/jphp.12001
15. Health Canada (2021) Home and community-based palliative care: Shaping the future from lessons learned during the COVID-19 pandemic. Retrieved from the Government of Canada website: https://www.canada.ca/en/health-canada/services/palliative-care.html
16. S Healy, F Israel, MA Charles, L Reymond (2013) An educational package that supports laycarers to safely manage breakthrough subcutaneous injections for home-based palliative care patients: development and evaluation of a service quality improvement. Palliative Medicine, 27, 562-70 https://doi.org/10.1177/0269216312464262
17. S Healy, F Israel, M Charles, L Reymond (2018) Laycarers can confidently prepare and administer subcutaneous injections for palliative care patients at home: a randomized controlled trial. Palliative Medicine, 32(7), 1208-1215 https://doi.org/10.1177/0269216318773878
18. BC Huisman, EC Geijteman, MK Dees, NN Schonewille, M Wieles, L van Zuylen, KM Szadek, A van der Heide (2020) Role of nurses in medication management at the end of life: a qualitative interview study. BMC Palliative Care, 19(1), 1-11 https://doi.org/10.1186/s12904-020-00574-5

References

19. BT Joyce, DT Lau (2013) Hospice experiences and approaches to support and assess family caregivers in managing medications for home hospice patients: a providers survey. Palliative Medicine, 27(4), 329-338 https://doi.org/10.1177/0269216312465650
20. M Kelley, G Demiris, H Nguyen, DP Oliver, E Wittenberg-Lyles (2013) Informal hospice caregiver pain management concerns: a qualitative study. Palliative Medicine, 27, 673e682 https://doi.org/10.1177/0269216313483660
21. D Lau, JD Kasper, JM Hauser, C Berdes, C Chang, R Berman, J Masin-Peters, J Paice, L Emanuel (2009) Family caregiver skills in medication management for hospice patients: a qualitative study to define a construct. Journal of Gerontology: Social Sciences, 64(6):799-807 https://doi.org/10.1093/geronb/gbp033
22. DT Lau, R Berman, L Halpern, AS Pickard, R Schrauf, W Witt (2010) Exploring factors that influence informal caregiving in medication management for home hospice patients. Journal of Palliative Medicine, 13(9), 1085-1090 https://doi.org/10.1089/jpm.2010.0082
23. L Lee, C Headland (2003) Administration of as required subcutaneous medications by lay carers: developing a procedure and leaflet. International Journal of Palliative Nursing, 9(4), 142-149. https://doi.org/10.12968/ijpn.2003.9.4.11504
24. M Lucey, R McQuillan, A MacCallion, M Corrigan, J Flynn, K Connaire (2008) Access to medications in the community by patients in a palliative setting. A systems analysis. Palliative Medicine, 22(2), 185-189 https://doi.org/10.1177/0269216307085722
25. R Marvin, S Grove, A Spathis, S Barclay (2017) P-42 injectable medication at the end of life: a common task for generalist community clinicians. BMJ Supportive Palliative Care, 7(Suppl 1):A15-A16. http://dx.doi.org/10.1136/bmjspcare-2017-00133.42
26. S Payne, M Turner, D Seamark, C Thomas, S Brearley, X Wang, S Blake, C Milligan (2015) Managing end of life medications at home accounts of bereaved family carers: A qualitative interview study. BMJ Supportive & Palliative Care, 5, 181e188 https://doi.org/10.1136/bmjspcare-2014-000658
27. K Pollock, E Wilson, G Caswell, A Latif, A Caswell, A Avery, C Anderson, V Crosby, C Faul (2021) Family and health-care professionals managing medicines for patients with serious and terminal illness at home: a qualitative study. Health Services and Delivery Research, 9(14) https://doi.org/10.3310/hsdr09140
28. M Rose, DC Currow (2009) The need for chemical compatibility studies of subcutaneous medication combinations used in palliative care. Journal of Pain & Palliative Care Pharmacotherapy, 23, 223-30. https://dx.doi.org/10.1080/15360280903098382
29. WJ Rusho (2004) Extemporaneously compounded sterile medications: relevance of new United States pharmacopeial standards to pain clinicians. Journal of Pain & Palliative Care Pharmacotherapy, 18, 69-76 https://doi.org/10.1300/j354v18n04_08
30. B Sheehy-Skeffington, S McLean, M Bramwell, N O'Leary, A O'Gorman (2014) Caregivers experiences of managing medications for palliative care patients at the end of life: A qualitative study. American Journal of Hospice and Palliative Care, 31(2), 148-154. https://doi.org/10.1177/1049909113482514
31. C Short, A Scott (2015) OA9 Impact of medication safety in the palliative care home setting-the carers' perspectives abstract. BMJ Supportive & Palliative Care, 5(Suppl 1):A3 https://doi.org/10.1136/bmjspcare-2015-000906.9
32. E Wilson, G Caswell, N Turner, K Pollock (2018) Managing medicines for patients dying at home: a review of family caregivers' experiences. Journal of Pain and Symptom Management, 56(6), 962-974 https://doi.org/10.1016/j.jpainsymman.2018.08.019
33. Government of Canada. Narcotic Control Regulations, C.R.C., c.1041. https://laws-lois.justice.gc.ca/eng/regulations/C.R.C._c._1041/index.html

Appendix

Nursing decision-making factors in preparation of subcutaneous medication for people receiving palliative care at home

Assumptions

1. This person's goals of care are supported by receiving subcutaneous medications in the home.
2. A decision by the prescriber has been made that subcutaneous medications are required; subcutaneous route is determined to be the best route for this person on this visit. The person and family caregivers have consented to have subcutaneous medications.
3. Equipment for subcutaneous medications is available.
4. Nursing decisions about pre-drawing is made at every visit.
5. The context of community practice with opioids and medications has some differences compared to institutional settings. E.g.:
    - Instructions for family caregivers include drawing up multiple doses from a vial to not waste medications.
    - Instructions for disposal of equipment and medications.
    - The regulations governing opioids and subcutaneous medication administration at home are distinct from the requirements of medication administration in institutional settings.[33]

Decision-making considerations

- The priority of the following factors and key aspects will depend on the individual situation.
- Only key aspects are listed under each factor and not all potential aspects related to the factor.
- These factors in nursing decision making and should not be used or viewed as barriers in person receiving care. Many can be mitigated, and creative approaches implemented to ensure care is oriented by the person's goals of care and willing family caregivers can be supported while ensuring safety within the home and the community.

Appendix

Factors

Person's goals of care – goals in relation to their illness experience.

- How do the person's current goals of care affect the decision?
- How does, 'What is most important to the person?' affect the decision?
- How do the person's priorities (e.g. location of care) affect the decision?

Family Caregivers' willingness – Family caregivers' willingness to prepare and or administer subcutaneous medications for symptom management.

- Family caregivers understand what is involved in the task now and over time
- Family caregivers desire to take on this aspect of care with the available nursing support
- Family caregivers consider competing demands in family caregivers' lives
- Willingness to manage the number of subcutaneous medications

Person's condition and predicted time frame – The anticipated time frame for family caregivers to be involved in preparing/administering subcutaneous medication with people' current health condition.

- Symptom management requirements (e.g. temporary treatment until symptom resolved or ongoing symptom treatment)
- Palliative Performance Scale (PPS)
- Prognosis
- Anticipated next location of care (e.g. home going to hospice, home to long term care)

Safety in the home – Safety in the home related to the subcutaneous medications and supplies.

- Children and/or pets in the home
- Potential for substance misuse/diversion
- Disposal of syringes and medications

Family caregivers' cognitive capability – Family caregivers' cognitive capability in preparing and administering subcutaneous medications for symptom management.

- Family caregivers' cognitive ability to understand and follow instruction
- Family caregivers' organizational skills
- Family caregivers' literacy level
- Family caregivers' ability to teach others who are involved in person's care

Family caregivers' functional capability – Family caregivers' functional capability in preparing and administering subcutaneous medications for symptom management.

- Dexterity and eyesight of family caregivers for drawing, administering, and recording subcutaneous medication
- Eye-hand coordination and fine motor skills
- Ability to maintain aseptic technique

Family caregivers' mental well-being – Family caregivers' mental well-being related to preparing and administering subcutaneous medications for symptom management.

- Family caregivers' mental well-being to handle potential stress and anxiety associated with tasks of symptom management with subcutaneous medications
- Attitudes and beliefs around the use of administering subcutaneous medication held by family caregivers that could impede family caregivers' mental well-being
- Access to psychosocial support
- Family caregivers' well-being in relation to person's declining condition

Appendix

Person's environment – Person's environment including the home and the broader community.

- Person's living situation
- Geographical location (i.e. rural, remote, urban)
- Phone access for nursing support
- Availability of pharmacy (e.g. medication supplies, hours available)

Nurse availability – The availability of nurses to do home visits for symptom management and support.

- Next likely planned nursing visit
- High risk that the next nursing visit will be canceled or delayed
- Time available in this visit to teach willing family caregiver/s to administer subcutaneous medication, and to monitor the effectiveness of medication.
- Time available in this visit to teach willing family caregiver/s to draw injectable medication into syringes
- Nursing support available between home visits to help family caregivers troubleshoot including after hours and overnight support
- Nurse availability to alleviate caregiver burden

Backup plan for symptom management – Back up plan for symptom management in case of a barrier to administer subcutaneous medication/s.

- Who else could help when primary family caregivers are unable to do so
- Alternative medication or alternative route to troubleshoot when nurse unable to visit due to various reasons
- Alternative to home if required

Nurses' knowledge, skill, ability, confidence to teach family caregivers related to subcutaneous medication for palliative symptom management.

- Palliative care education for nurses
- Nurses' own skill and experience with subcutaneous injections
- Access to standardized teaching resources
- Communicate effectively with family caregivers through speaking or language support resources
- Time allocated for teaching family caregiver/s

Policies and guidelines – the use of existing policies and guidelines for nursing decision making related to subcutaneous medication preparation and administration by family caregivers.

- Legislations and regulations
- College standards
- Organizational policies

Medication stability – Medication maintaining its intended therapeutic properties such as strength, quality, and purity after being drawn into a syringe.

- Storage method (temperature, light exposure)
- Length of medication stability (often determined by manufacture/research studies)
- Reduced effect of administering medications that have not maintained its intended therapeutic properties

Medication sterility – Medication free of microbial growth.

- Time from medication preparation to administration
- Potential for infection/inflammation at injection site
- Use of proper aseptic technique

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