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Covert Administration of Medication to Persons with Dementia: Exploring the Ethical Dimensions

Jenny M. Young and David Unger

ABSTRACT

The literature, although sparse, reports that covert administration of all types of medications is prevalent in nursing homes. Whether it is ever ethically defensible, however, to administer medications covertly to persons with significant dementia is a complex and contentious question. Some scholars contend that deception is inherently wrong and is never acceptable, while others believe that deception is intrinsic to providing care to persons with dementia. With an aim to begin to reconcile these polarized positions and to objectively study this contentious issue, the authors undertake an ethical analysis of the covert administration of medications by utilizing the principles of respect for autonomy, nonmaleficence, beneficence, and justice. Our approach examines covert administration within the context of all persons with significant dementia who are administered medications, and is aimed at providing ethical and practical guidance to clinicians who, when confronted with a patient who refuses medication, must choose the "least bad" option from among various courses of action, all of

which have ethical implications. Components of a possible guideline for practice are proposed.

INTRODUCTION

Covert administration of medication (CAM) occurs when prescribed medication is intentionally administered to patients without their knowledge and, by extension, without their consent. As truth telling is the foundation on which careprovider-patient relationships are built, CAM may be perceived as deceptive, a breach of trust, an abuse of power, an affront to individuals' autonomy, and inherently wrong.

There is no question that capable persons make their own decisions about medications and should never be administered medications covertly. Patients who lack the capacity to make medication-related decisions, that is, those who cannot integrate information to the degree that they can make an informed choice, include individuals whose capacity has waned (dementia), fluctuates (mental health disorders), or has always been impaired (severe cognitive disability). Each of these groups has unique characteristics that require different considerations regarding the administration of medications. Our discussion is limited to persons with dementia who no longer have the capacity to make medication-re-

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lated decisions. Whether CAM is justifiable with this population is a complex and controversial question. We examine this question from pragmatic and principlist-based perspectives.

WHOM ARE WE TALKING ABOUT?

A fictional case is described to illustrate our discussion and conclusions.

Mei Ling lives in a nursing home. She has vascular dementia, severe hypertension, and a significant cardiac history. She is receiving oral antihypertensive medications, the optimal therapy to treat her hypertension and prevent worsening of her vascular dementia. For the past three days, however, Mei Ling has spit out these medications. If she continues to spit them out, she is in imminent risk of further cognitive decline and other medical co-morbidities.

Starting with the assumption that these medications contribute to Mei-Ling's well-being, the care team has six potential courses of action.

1. Acquiescence: Give in to her current protestations and walk away.
2. Pleading: Continue to offer the medications in hopes that she will at some point swallow them.
3. Offering incentives: Offer her ice cream as a "reward" if she takes her medications.
4. Coercion: Place the medications in Mei Ling's mouth and physically coax her to swallow them by stroking her throat or restrain her to administer the medications by injection.
5. Compromise: Administer a transdermal nitroglycerine patch, a less invasive but less effective treatment for her conditions.
6. Covert administration: Crush the medications and mix them with juice that Mei Ling will cheerfully drink, ignorant of any subterfuge.

Mei Ling's scenario and possible responses, or variations on them, play out in North American institutions every day. This article will focus on the option of covert administration, recognizing that a comprehensive discussion of CAM must examine its practice in two contexts: the clinical context of all persons with dementia who are incapable of decision making regarding medications, and the practical context of all possible options of administering medications to these individuals.

We therefore do not see CAM as a concern that exists as a stand-alone theoretical problem regarding truth telling versus deception. CAM is positioned along an ethical continuum of interventions that begins with easily administering medications to a

passive, uncomprehending individual, and may lead to either forcible or covert administration to an individual who resists. In clinical settings, caregivers do not have the option to do nothing when confronted with an individual who refuses medications. They must choose from a number of options, recognizing that even walking away from a patient is a commitment to a course of action, while knowing that ethical complexities are inherent in all of the options.

THE SCOPE AND NATURE OF COVERT ADMINISTRATION OF MEDICATION AS REPORTED IN THE LITERATURE

In looking at empirical studies about CAM, there is a startling paucity of literature from North America. Certain countries have taken a lively interest in this topic, however, and there is a body of literature from Europe that relates to the scope of CAM in nursing homes. One literature review that examined eight articles and one inspection report that provided original data concerning the frequency and details of CAM with older adults found that CAM occurred in 43 to 71 percent of nursing homes, and that 1.5 percent to 17 percent of nursing home residents were reported to have received medications covertly.¹ The types of medications that were covertly administered included antipsychotics, anxiolytics, hypnotics, and those for physical disorders such as hypertension, physical pain, and epilepsy. Three of the articles described the population of residents who received medication covertly to be more likely to be receiving antipsychotics, and to have severe cognitive impairment/dementia, aggression/agitation, and diminished capacity to perform activities of daily living.

The Scottish Care Inspectorate reported that the incidence of CAM increased from 11 percent of residents in nursing homes in 2010 to 13 percent of residents in 2011, and to 16 percent in 2012.² Some residents received as many as 10 medications covertly.

The practice of CAM is often secretive. It is decided upon by nursing staff alone, and not discussed with colleagues, recorded, or monitored.³ It is suggested that a culture of fear may surround CAM as, lacking guidelines, staff may be fearful of litigation and so practice it in secrecy.⁴ Even leaving aside the issue that secrecy may contribute to and increase the likelihood of adverse events and abuse, the secretive nature of this activity, in and of itself, may provoke moral outrage. This has prompted some countries, such as England and Scotland, to develop practice guidelines.⁵ However, there are as yet no empirical data or outcome measures to help define

best practices when an incapable patient refuses medications.

Despite, or possibly because of, the lack of empirical data, CAM is a divisive and polarizing topic, and scholars are often decisively and firmly for or against the practice. Some scholars contend that deception is never acceptable and that it is a form of treachery that undermines personhood,⁶ while others believe that, as a last resort, individuals' best interests may guide decision making.⁷

Although it does not specifically address CAM, there is an abundant literature regarding lying to and deceiving people living with dementia.⁸ This literature is also divided as to whether lying is justifiable in defined circumstances, such as when an individual repeatedly asks for a deceased spouse. James and colleagues' exploratory study of 112 staff working in elder care settings found that only four of the 112 stated that they never lied.⁹ Of these, 90 percent stated that they told lies to ease residents' distress, and 75 percent had done so to ease caregivers' distress. It was noted that lying can lead to problematic outcomes, including increased confusion due to inconsistencies in the lies that are told, distrust between residents and staff, and tension and confusion with family members.

Even if there is a positive therapeutic outcome from lying—for example, relief of residents' distress—a conflictual relationship has been identified between this therapeutic value and the ethics of lying. While some believe that a positive outcome is a legitimate reason to lie, others believe that lying can never be ethically supported,¹⁰ that it depersonalizes and disrespects the person with dementia,¹¹ and that suffering is a part of being human.¹² These different perspectives about lying are equivalent to the polarized and dichotomized positions regarding CAM: deception leading to an improved health outcome versus truth telling as an intrinsic value, regardless of the outcome.

Importantly, there is also literature that has examined lying and deception from the perspectives of persons living with dementia.¹³ It found that a minority of participants described lying as always unacceptable. The majority considered lies to be acceptable if told in an individual's best interest. "Best interest" was defined as a complex notion that included, among other factors, the cognitively impaired person's awareness of the lie and the caregiver's motivation in lying.

We believe that there is no need for a strong dichotomy between supporting and opposing CAM, and that the solution to the conundrum of CAM is not "yes" or "no," but rather, "it depends." We ac-

knowledge that "it depends" is a vague, unsatisfying, and value laden term, but hope to give it some firmer structure and parameters by elaborating further on the complex context in which CAM might be considered, and through an analysis in light of ethical principles. We believe this will help in establishing whether CAM is ever ethically justifiable, and, if so, on what basis.

DEFINING THE ETHICAL ISSUES

If we are to make the case that CAM is an ethically defensible practice, we must find ways to justify deception that are more persuasive than the case for truth telling (which we interpret to encompass not deceiving) in the population we are considering, namely, those persons who are decisionally incapable regarding medications and who resist beneficial medications.

Blackwell has argued that "if someone has severe dementia, everything is deception."¹⁴ In terms of accepting the administration of medication, the population of persons with severe dementia ranges from persons who passively accept medications to those who actively resist. All of these individuals are, by the very defining features of their diagnoses, uninformed regarding their medications, and any uninformed administration of medication, whether passive or forceful, is an ethical concern. CAM is one means to administer medications to uninformed patients. It is arguably more ethically suspect than administering medications to a passive incapable individual; but the fundamental concern, the heart of the matter with all of this population, is lack of informed consent—as illustrated by the following fictional example.

Bill has advanced Parkinsonian dementia and cannot tell the difference between medications and food. He unquestioningly swallows medications he is given, as well as passively accepts intravenous or topical medications. Bill no more understands why he accepts medication than Mei Ling understands, in any rational way, why she resists them. From Bill's perspective, whether the medications are in plain view or are hidden in food is irrelevant.

Bill is part of an enhanced context by which CAM should be considered. He, not a decisionally capable individual, is the backdrop for considering Mei Ling's situation.

Further, not only must we distinguish between the complexities of CAM versus passive administration, we must also find a place of equanimity within a spectrum of morally ambiguous behaviors that make up the continuum of CAM. These dubi-

ous activities run from the relatively benign of concealing bowel medications in the Jell-O of a patient like Mei Ling (which may engender some moral discomfort), to that of concealing antipsychotics in the juice of an individual with challenging behavior (which may engender significant moral conflict and doubt). An appropriate and proportionate response to these varied circumstances is called for.

We begin with two assumptions. (1) Based on our clinical experience and that of our colleagues, CAM is happening in the course of usual clinical practice. We take it as self-evident that clinicians can relate to the scenario of Mei Ling. (2) CAM is driven by good intentions aimed at promoting good health outcomes or increased well-being. That it happens and that clinicians are well-intentioned do not supply sufficient ethical justification. Our ethical analysis of the practice of CAM is based upon application of the principles of respect for autonomy, beneficence, nonmaleficence, and justice.

Respect for Autonomy

The moral importance of truth telling, including not deceiving, is crucial to the principle of respect for autonomy. Truth telling has two important components. First, it demonstrates respect for and honors the inherent dignity of persons. This is a duty to others that many believe should never be compromised. However, the generally accepted ethical position regarding truth telling in healthcare is less clear cut. It posits that healthcare providers have a *prima facie* (as opposed to an absolute) duty to tell the truth—that is, to tell the truth unless there are significant reasons and justifications for not doing so.¹⁵ These justifications may include preventing harm and benefiting the health and well-being of the patient as well as recognizing justice interests of the patient. We will examine these competing interests in the sections that follow and consider how they intersect with the principles of beneficence and nonmaleficence as well.

The second consideration with respect to truth telling is its consequentialist grounding. Truth telling enables people to govern their own lives (exercise their autonomy), as they are provided with information necessary to make informed decisions. But we encounter significant challenges in this regard when working with individuals who do not have the capacity to make contemporaneous medical decisions. Truth telling with an individual who is unable to comprehend the substance of the information provided cannot honor an individual's autonomy in terms of informed decision making, and the consequences of poor output based on poor in-

put are not trivial when it comes to life-altering medical conditions.

Incapacity may, in fact, subvert a person's long-term goals and values, and hijack previous capably and autonomously conceived life projects. For example, Mei Ling may have been a very medically oriented person who faithfully adhered to prescribed treatments, and only now in her state of decline does she oppose beneficial treatments. Acquiescing to her protests, while pragmatically easier, is an affront to her previous autonomously derived values and unimpeded actions. Alternatively, if a person was always clear about not being interested in particular medical treatments, administering the treatments either covertly or overtly, simply because the person has lost the capacity (mental or physical) to oppose the treatment, is also ethically unacceptable. In either case, one's current incapacity should not compromise one's durable life choices.

It is possible to overcome these ethical and practical challenges because autonomous decision making can outlive a person's decisional capacity in two ways. The first is through a formal advance care plan. This should be taken into account for all decision making for incapacitated persons. (Indeed we will suggest below that an advance care plan could include explicit reference to the permissibility of CAM.)

The second entity that preserves a person's autonomy is the substitute decision maker. Although it is recognized that a substitute decision maker is an imperfect substitute for a capable patient, a substitute decision maker is the next best thing, and one should be sought to provide input in all cases when CAM is being considered. If a patient made wishes about medications when capable, consideration of these wishes will accomplish much in satisfying a careprovider's duty to respect a patient's autonomy. If no explicit direction was given, the substitute decision maker may yet make a "substituted judgment" that reflects the beliefs and values generally held by the patient.

It is recognized that few advance care plans will speak directly regarding medications and CAM, and that substitute decision making is a complex and difficult task. But although an individual's beliefs and values may not directly address CAM, they may give guidance regarding what the person would want in terms of life-supporting medical interventions. If any of those interventions involve medications, the issue of CAM may become a legitimate consideration in the care plan of a loved one.

If there is no way to know what a patient's wishes or values were when she or he was capable, a sub-

stitute decision maker will need to make a “best interest” decision grounded in what a “reasonable person” would want. The fulcrum of such a decision is the balance point between benefit and burden for a given individual in a given set of circumstances, and so our discussion turns to an examination of these corresponding principles.

Beneficence and Nonmaleficence: Weighing Harms and Benefits

There are no perfect drugs; every medication has potential adverse effects. The first consideration in all cases when medication is refused by a patient is whether the medication is effective and necessary, notably given the questionable effectiveness and significant morbidities that are associated with many medications when they are used with elderly persons. Use of medications such as stool softeners or laxatives might be straightforward in that they carry few risks and might prevent considerable discomfort from constipation. Medications such as antipsychotics, however, carry significant risks, and these risks need to be balanced against possible harms if the medications were not administered. Such harms might include frightening paranoid ideation leading to fear and mistrust of caregivers, or aggressive behavior that might necessitate physical restraint including a locked ward.

All medications require a rigorous harm/benefit analysis regardless of how “benign” they may at first seem. Our starting assumption with respect to CAM is that medications are only recommended when it is believed they will enhance well-being; that is, their putative benefits outweigh the risks of harm. Further, these benefits and harms must relate to this particular patient. In some cases, especially involving aggressive behavior, decreasing harm to others (such as staff or other patients) may be suggested as a legitimate reason to medicate a patient. While we acknowledge that the safety of others is very important, the goal of administering any medication (including covertly) must be aimed first and primarily at the health and well-being of the patient who is receiving the medication.

Finally, any medication should be recommended only when other, less intrusive means to meet the goals of the medication are not available. For example, it should be asked if increased activity or socialization would be effective in decreasing agitation before any medication is administered.

There are novel risks associated specifically with CAM. As recipients are unaware of the medication being administered, they may not be able to recognize or articulate side-effects. They are, by the very

defining features of this situation, unaware of the cause, and so cannot report the effect. Further, changing the administration by crushing or dissolving a medication may change its absorption and pharmacodynamics and augment adverse effects or diminish therapeutic effects. As well, the patient may taste the medication and lose trust in the care team, or may refuse to eat and drink altogether.¹⁶

Weighing harms and benefits requires more than merely looking at the adverse effects of molecules being put into bodies. When weighing benefit and harm, we must look at the overall benefit and harm of one option in relation to others, because sometimes we are forced to merely choose the least bad option. Recall the options presented in the case of Mei Ling. These include acquiescence to her protests and thereby missing beneficial medications; pleading with her and risking missed dosages and development of a frustrating and possibly adversarial relationship; the use of incentives, which can be seen as a demeaning technique one might use with a child; physical coercion, possibly causing physical and emotional harm to the patient (in particular a frail elderly person); and compromise with a less effective medication, decreasing health benefits.

In terms of beneficence and nonmaleficence, we should ensure that the option chosen is effective (and necessary), that it does not cause more harm than that which it seeks to prevent, and that it is the least intrusive (in terms of both alternatives to medication and mode of administration of medication). If these conditions are met, we can then weigh the potential good of administering the medication against the potential harms to the dignity of the person in using deception (or incentives or physical coercion).

A Question of Justice

One conception of the principle of justice is treating “equals” equally and “unequals” unequally.¹⁷ That is, while all people have equal moral standing, the rejection of a medication by a capable person is not equivalent (“equal”) to the rejection of a medication by someone who lacks decisional capability, and therefore requires a different response. If a medication is only administered to capable persons, individuals who are not capable may suffer from being denied care,¹⁸ which would be, as Treloar, Philpot, and Beats state, “to give an incapacitated patient the responsibility of capacity.”¹⁹ Individuals who lack the capacity for fully informed consent for treatment (or, in Mei Ling’s case, who refuse treatment) are not able to express their choices, but they are still owed the same high standard of qual-

ity medical care as those who can speak for themselves.²⁰ Although CAM may be viewed as an infringement of an individual's rights, so may the deprivation of needed medical care,²¹ and the denial of that care may be seen as discriminatory. Again, even if we subscribe to this conception of justice in the case of incapable persons, we must still weigh the tangible biological benefits of covertly giving medications against the more intangible intrusion on dignity inherent in any deception.

Procedural justice must also be considered. CAM involves situations in which hierarchies exist: when paternalistic decisions are made by physicians and nurses who hold significant power, and who measure and weigh value-laden constructs such as "benefit" and "burden" according to their own interpretation. Careproviders must often make expeditious unilateral decisions based on professional judgment, but when CAM is contemplated, fair process demands rigorous explicit decision making: transparent, inclusive, accountable, respectful, and (ideally) guided by robust policy. One means by which to attend to this procedural justice is to involve others in the decision making. Persons who are and have been important to the patient should be part of this process. Consulting with a neutral patient advocate, risk manager, and ethics representative should also be considered, particularly if a patient has no other relationships. A group brings diversity of perspectives to the decision at hand, thereby promoting rigorous consideration of all facets of the competing ethical principles.

Moving beyond involving others in decision making about individual patients, it would also be in the interests of transparency to openly explain to all patients, families, and staff how decisions are made for patients who are not able to make decisions for themselves. The scope of these decisions would be broader than only those related to medications, and would include interventions such as surgery or feeding regimens, but medication non-adherence would ideally be included as one of the circumstances when decisions would be made by others. A transparent approach to the process of making decisions for others, including the possibility of CAM, would remove much of the taint of secrecy and subterfuge and would likely cause some patients who are capable to clarify their wishes in the event of future incapability.

ETHICAL SUMMARY AND NEXT STEPS

Ethical discernment regarding CAM involves balancing beneficence and nonmaleficence, measur-

ing these against respecting personal autonomy, and taking into account the broadest societal conceptions of justice and applying them at the level of the unique individual.

There are clearly situations when CAM is not ethically acceptable, such as employing it for the convenience of staff or because of inadequate staffing levels. However, if it is based on the unique needs and circumstances of individual patients; if the patient's autonomy, both in terms of respect for their dignity and in relation to decision making, is honored as much as possible; if the benefits of CAM outweigh its possible harms in terms of the alternatives used to address medication non-adherence; and if a fair, open, and principled process is followed, we contend that there are many circumstances when CAM to incapable persons with dementia can not only be both clinically and ethically justified, but, given the alternatives, the most respectful and just course of action.

Because we believe CAM to be ethically defensible in certain circumstances, and given that CAM is being utilized in our institutions with varying degrees of acknowledgment and acceptance, we urge professional bodies and healthcare organizations to begin to craft principled, inclusive, and transparent guidelines on this important issue. As noted earlier, Scotland, and Northamptonshire and East London in the United Kingdom, have recognized that CAM is taking place in their facilities and have drafted guidelines for its practice.²² What we propose follows from this solid work.

Components of a Guideline

We suggest that guidelines for CAM should be a practical interpretation of the ethical analysis we have undertaken. The guidelines should position CAM near the end of an ethical continuum and decision-making process that, in broad strokes, would involve the following.

First, the refusal of medications by *all* persons, including those who are capable, should be examined. With a nod to the principles of beneficence and nonmaleficence, the utility and necessity of all medications must be carefully scrutinized, irrespective of whether CAM may be an option or whether a patient is decisionally capable.

If a medication is truly necessary, document, investigate, and attempt to remedy the reasons for refusal—and diligently ensure that there are no less intrusive means to meet the goals of the medications.

Next, examine decision making about medication for *all* incapable persons, including those who passively accept them, thereby ensuring that au-

tonomy is respected as much as possible for all persons who cannot make informed decisions for themselves.

For *all* persons who are incapable, examine advance care plans for directives on medications and, as appropriate, obtain consent from a substitute decision maker. Involve family, friends, and others who know the patient in the discussion (for example, family physician, case manager) and include an advocate, ethics consultant, and others as would be in the patient's interests.

Lastly, consider *all* options (including CAM) for those decisionally incapable patients who refuse medications. This step respects the principle of justice and the right of these individuals to receive care, even though they currently appear to reject it, and explores in more detail the harms and benefits of all possible options.

When a patient refuses medications, consider the use of incentives, less intrusive alternative medications, and covert versus forceful administration of medications. When CAM is decided upon, consult with physicians and pharmacists to determine the safest mode of administration. Monitor medications in a structured way and document CAM.

These steps are a rough framework for guidelines. Details need to be worked out for various settings, populations, and individuals. For example, the question of how often covert medications should be reviewed and monitored may depend on the type of medication (for example, a blood thinner versus an iron supplement) and the frailty of the patient. Who needs to be involved at each decision point may vary depending on whether there is general consensus regarding the patient's care plan or discord between the parties.

To avert moral distress, all persons involved in CAM should understand the reasoning and justification for it. Some staff may believe that CAM is fundamentally wrong and experience moral distress when required to carry it out. However, it must be remembered that not administering medications to an incapable person may also be morally dubious and cause distress. Following the suggested ethical process will go some way in both preventing and alleviating moral distress.

CONCLUSION

While CAM is a difficult and divisive issue, we believe that it can be ethically justified in certain circumstances in the interests of justice and with attention to individuals' autonomy and best interests. We recognize that this conclusion carries in-

herent risks of unwanted and potentially harmful intrusions in individuals' lives, but we believe that the safeguards proposed in the guidelines will ameliorate many of these concerns.

We also suggest that administering medications to *all* persons with decisional incapacity, not only those who resist, should be scrutinized in a comprehensive manner.

With an eye to the future, we strongly recommend that clinicians pre-emptively address this issue by exploring attitudes toward CAM with their patients while their patients have capacity and are drawing up advance care plans.

Finally, CAM is an area that begs for more investigation and analysis. In settings where guidelines for the practice of CAM exist, analyzing the use of these guidelines and the outcomes when the process is used would make a valuable contribution to the knowledge base about CAM. Research on the prevalence and characteristics of the practice of CAM in North America and beyond may offer insights into when and why CAM is practiced and help guide future recommendations and decision making protocols.

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