Mary, an 82-year-old with mild dementia, receives daily care, including bathing, dressing, and toileting from Wanda, a home health aid. Wanda, a 27-year-old single mother with three children, is ambivalent about her visits with Mary. On the one hand, Mary treats Wanda as the child she never had, and occasionally she gives Wanda tokens of appreciation, including chocolates for Wanda's children, tips, and objects Wanda knows are special to Mary. On the other hand, Mary is cranky when Wanda is running late because of child care issues. Mary often barks demeaning orders about how she wants things done. Sometimes Wanda overhears Mary's husband, John, making cruel remarks to his wife and has observed threatening gestures. On a recent visit, Wanda noted bruises on Mary's arms and head, supposedly the result of Mary's fall. While Wanda is suspicious about the explanation for those injuries, and is increasingly worried about Mary's safety, she is hesitant to speak to anyone at her agency for fear it could jeopardize her relationship with Mary and John and possibly result in Mary being placed in a nursing facility.

If this case were brought to a hospital ethics committee, the moral issues specific to home care might be overlooked. For example, a hospital ethics committee would likely focus on Mary’s dementia and her capacity to make decisions. If she were determined to be incapacitated to make decisions about activities of daily living, the ethics committee would discuss whether John—given his surly temperament—was the appropriate proxy decision maker. As important as these issues are, they do not reflect the moral issues faced by home health providers. Therefore, it is useful for ethics committee members to place themselves in the shoes of those who work in non-acute settings, and attend to the particulars of this distinctive setting. What are the special features of home care and how would attentiveness to these features reframe the ethical insights of acute care committees?

First, let us attend to the setting, because the home is not an institution. Attentiveness to the setting—the home—recasts our thinking on the obligations and limits of institutional power. The setting changes the nature and priority of institutional obligations. The home is Mary’s turf, not the hospital’s. Therefore, home care ethics committees must explore where institutional moral responsibilities for Mary’s health begin and end. For example, how responsible are they for Mary’s safety? Since Wanda is on Mary’s turf, how alert must Wanda be so as not to overstep her authority and act in a coercive manner—an activity that is more possible in an institutional setting, but no less justifiable.

The setting also recasts power relations. In the acute care setting patients are not on equal footing with healthcare professionals, whose training and expertise creates power imbalances which institutions are morally obligated to keep in check. In home care, Mary and Wanda are on more equal footing. In fact, Mary’s home is her castle (indeed at times she treats Wanda as her serf).

Additionally, Wanda is on the low end of the wage and education scale and can be manipulated and even harassed by Mary because in the home care context the power shifts to the patient. Consequently, the home care agency is obligated to place checks on the patient’s power. For example, the agency should be more attentive that home health aids are neither exploited nor abused, and they should train them how to respond appropriately. As a consequence of the different setting, much of acute care ethics reflects on patient’s rights, but in home care moral consideration focuses on the caregiver as much as those who are cared for.

Another important difference derives from the person of the caregiver. In home care, more than 75% of the care is given by informal, unpaid, family caregivers (mainly women), who work all-day, everyday keeping clients like Mary out of nursing homes. Home health aids need to engage these essential caregivers, not alienate them. Home health workers attention to the needs of the client and importance of the family can recast important values. For example, acute care ethics has so much focused on the value of patient autonomy that the important value of the family as an essential ingredient of caring and curing can be under valued.

Enlisting the family also creates a two-edged sword. On one side, home care patients need the assistance of families because they assume the cost and burden of care and help keep patients out of nursing homes. On the other side, there exists the possibility that the patient may be coerced or abused by these same family members. Balancing the good and bad creates conundrums for home health workers about whether and when they should intervene. Beyond this moral issue, the utilization of the family as a source of care extends the scope of potential ethical problems outside patients-professional conflicts. For example,
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home care ethics committees have an opportunity to reflect on the ethics of a social policy that under funds what most frail and vulnerable people desperately want, (namely, to be in their own familiar home with their family and not in an institution), and simultaneously stresses family caregivers.

The type of care provided by home care agents highlights both moral virtues and risks. Unlike acute care, which provides high-tech therapies and interventions, home care relies in large part on non-invasive interventions such as listening, acknowledging, respecting, and comforting. One of the hallmarks of home care is that caregivers get to know clients intimately, and intimacy is an essential asset in caring. These simple, non-dramatic behaviors are virtues that go a long way in promoting the dignity and respect of the patient, and acute care ethics committees often do not have an opportunity to reflect upon them.

With these home care virtues come moral risks, especially regarding employees with less professional training. Consider Wanda’s innocent acceptance of candy or tips from Mary in part because of their almost mother-daughter-like relationship. While Wanda may have been informed at orientation about a “no gift acceptance” policy, she might be confused about how to balance intimacy with professional boundaries.

Training and mentoring of employees is not a central focus of acute care ethics committees. However, because home health workers work in private settings, and are therefore outside institutional scrutiny, professional training for such workers becomes an elevated moral issue. When a para-professional like Wanda receives roughly 24 hours of total training, the minimum amount required by her state, it is doubtful whether Wanda can be clear about how to balance HIPPA privacy requirements with state regulations to report suspected abuse. Insufficient training and mentoring could affect Wanda’s understanding of confidentiality. For example, if Wanda believed that the obligations of confidentiality are similar to a seal of confession requiring strict confidences, this could be a potent risk to Mary if abuse was occurring. Thus, institutional obligations surface here in several ways. First, the institution is obligated to be sure that employees understand state regulations of what constitutes abuse and what is reportable, and that observed abuse must at least be reported and discussed internally. Second, the institution should help employees become aware that every professional has different perceptions of what constitutes abuse/neglect. Finally, institutions might have an obligation to “script” employees on difficult situations, for example, how to diplomatically remind families that there is a patient/client advocate, namely, the home health worker.

Home care ethics might be off the moral radar of acute care ethics committees. However, there is much to learn from walking a mile in the shoes of those working within home care. Moral issues that are non-dramatic in acute care come to the foreground in home care. Attention to the virtues found in home care—such as connectedness, nurturance, solidarity, and response to vulnerability—are virtues to be promoted in all care settings. Most importantly, new settings recast moral obligations and provide insight into whether similar problems occur in all health care settings but simply never catch an ethics committee’s attention because of the presence of more dramatic life and death issues.

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