Ethical Issues in Home Care

Summary and Overview of presentations and discussions at the Annual Meeting of the Canadian Bioethics Society October 28–31, 2004

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Executive Summary

Over the past few years, policy development and systemic restructuring have shifted the primary locus of health care from the Hospital and other institutionalized settings to the home. As a result of this shift care is now being provided by an array of caregivers, including health care professionals, less skilled paid care providers, and unpaid care givers, namely family and friends. Health care spending that accompanies this shift does not fall within the parameters and protection of the Canada Health Act, which has always dealt only with care provided by physicians and services provided in hospitals. While most provinces have chosen to cover some elements of home care, there is tremendous variation in the services covered and in the funding and delivery methods of such services across the country. In a time of dramatic switches of preferred sited of heath care it is important to have close monitoring in place to ensure equity is protected.

This shift of locus of care has significant impact not only on the patient, but also on those individuals, both paid and unpaid, who bear the increasingly heavy burden of providing care in the home setting. The impact and effects of this ongoing shift from institution to home as locus of care have not to date been adequately explored. The Canadian Bioethics Society made the very deliberate choice to take the emerging ethical and practical issues in home care as the theme for its 16th Annual Conference. Some of the main issues that were discussed include: the identity and role of the health care provider; the meaning and importance of home, including the complex relationships therein and the potential for depersonalization; issues that arise in complex home health care with children; and broad policy considerations in the home care context. This paper will serve primarily as a summary of the issues discussed in the plenary and concurrent sessions of the Canadian Bioethics Society's conference, and hopefully provide a foundation for further research in the vastly important and ill-defined area of home health care.

Background to this report

The Canadian Bioethics Society has members drawn from many disciplines. Many focus entirely on ethical issues, and may have a background in philosophy, theology, sociology, anthropology, law and so on. Many others have a background in health care delivery with an interest in ethics. The predominant groups in this section are physicians and nurses. Others still are health care professionals who have undertaken formal training in ethics, and focused almost all of their energy on ethical issues. The Society was founded in 1988, and one of its main events is the annual meeting. Within the annual meeting there are sessions led by invited plenary speakers, workshops presented by members and guests and smaller presentations developed by members. Outside the plenary talks there are seven concurrent sessions.

The overall organization of each annual meeting is in the hands of a local committee that manages the details of that specific annual meeting, and in turn is responsible to the CBS Executive. Each organizing committee of a CBS committee develops a theme. The organizing committee of the 16th Annual Canadian Bioethics Society took the theme of Home Care and Ethics. This theme was developed because the organizing committee saw this as an important issue of concern to many members, health care providers and members of the public. The theme developed by an organizing committee will lead to choices on who the plenary speaker would be and on some of the workshops. However many of the speakers will deal with bioethics topics other than the main theme. In other words at the conference in Calgary in October 2004 the theme was home care, prominence was given to this theme, but this was not the only topic discussed at the conference. A note of caution is required in assuming that issues in 'home care' are somehow different from issues arising in long-term care, nursing homes, group homes and so on. Many of the issues raised cross boundaries and it needs to be recognized that hospital care and home care are not in opposition but points on a spectrum.

The report is based on the authors' impressions of talks and sessions attended by them, and is limited by the topics available and the impossibility of attending all sessions. We therefore were dependent on, and grateful to, the various speakers. The report is an expansion of our notes and interpretation, supplemented by extensive discussion at the conferences and afterwards. While the talks were the starting point, the speakers may well disagree with our conclusions!

The specific request from Health Canada was to :
examine emerging issues in home care and end-of-life care based on the plenary and concurrent sessions of the Canadian Bioethics Society's 16th Annual Conference. The paper will examine ethical issues from the perspective of health care providers, family/informal caregivers and care recipients.

Acknowledgements

Introduction to the Report

Care in the home is an increasing focus for members of the public, whether as patients, family members, relatives or friends; health care professionals; politicians and health care administrators; and the media.   This is often presented as a new direction in health care provision, and in many ways this is true. In other ways this can be regarded as a rediscovery of an older paradigm of health care.   Before the early 20th Century care for the sick was almost always in the home. Physicians would carry out their assessment in the home, and subsequent care would usually be provided by family members. Those with sufficient financial resources might employ a professional care giver (nurse), but more often care for the sick family members was provided by relatives.

Those who could not be cared for in the home would be looked after in a variety of institutions. Thus the earliest hospitals were mainly to provide care for the poor. Hospitals in their modern form were first seen to some extent in the late 19th and early 20th Century, and quickly became central to health care delivery. In the later 20th Century this trend towards institutional care increased dramatically, and almost all health care was delivered in an institution. Although a small amount of home health care continued, such care was extremely limited. One of the reasons for the accelerated use of hospitals was the increased complexity in care being provided. This complexity was coupled with an increase in the success of treatment.   There was a marked development of technological aids to treatment, and at the same time a proliferation of health care professionals. For example physicians became specialized and sub-specialized, nurses developed special areas of competence, and many new health care professions developed. As these trends were developing, there was an impression that while treatment may have improved, the care being provided was less personal.

By the late 20th Century there was recognition of the trends and changes in health care, but also some discomfort with them. The public were demanding more emphasis on care rather than treatment, and were demanding more control over the details of their own health care. Costs were seen to be escalating. Given the demands of the public, and the perception that ways needed to be found to control costs, there was a turn towards home care. This was seen by many administrators, politicians and policy analysts as away of providing less costly care for patients such as the frail elderly, or those with chronic illnesses. The public focused not on costs savings (all of which are speculative), but on the impersonalization of institutions and their expectation that care would be better in the home.

Further developments in technology helped the trend towards an increase in home care. Some of these developments were simple. For example intravenous cannullae were developed that could stay in place for several days. A "cap" would be placed on the cannulla and individuals could then go about their daily

life quite unobtrusively. They might be seen by a health care professional once or twice a day when the cap would be removed and an intravenous injection given, perhaps of an antibiotic, the cap replaced and then the individual continued their activities. This simple development allowed severe infection to be treated at home. This and similar developments meant that significant populations no longer needed to be admitted to hospital. At the other extreme, many of the technological developments available in acute care were simplified, ways of monitoring improved, and patients with very complex care needs were then considered suitable for care at home. These included patients on assisted ventilation for respiration, whose care needs in terms of professional support are demanding whether in the home or the hospital. These complex patients often survived because of advances in medicine, and the resources applied to high-technology care. Resources for their continuing care are less readily available despite the moral imperative articulated by Evans: *every life we save commits us to providing care for that life as long as it lives.* Between the extremes there are examples of all sorts of conditions in all age groups managed at home

Given the lack of clear definition of what is and what is not home care, there is difficulty in clearly describing the population concerned and the ethical issues they face. In a number of talks at the Canadian Bioethics Society there was considerable overlap in the issues identified in home care, and in long term care. This overlap is understandable, especially when one realizes that it is overly simplistic to characterize the trend in health care as a shift from hospital based care to home care. In reality there is a switch in the site of care from the acute care hospital to many other settings including long term care settings, nursing homes, group homes, daycare, and care in the home. Many of the issues we identify as applicable to home care, are also applicable to these other settings and many of the patients/clients access services at multiple sites at the same time*.*

Shifts in payment for various aspects of health care are problematic, difficult, and lag behind changes in practice. Home health care is a particularly difficult example as it is not included within the Canada Health Act which focuses on physicians' services and hospital care. However, in response to both the increase in health care costs and public pressure, provinces have developed a variety of different schemes for some aspects of home care, particularly end-of-life and palliative care, and to meet specific local circumstances. Funding for other parts of home care comes from a plethora of different payment schemes, with a wide mixture of public and private funding sources.

Health care delivery has been impacted by changes in health care organization, public demands and changes in technology. Specifically, the development of regionalization means that in some provinces if home health care is seen as less costly than institutional care, there is a major incentive on the part of regional health authorities to pay for at least some home care.

Providers of home health care come from a variety of backgrounds and with much less uniformity than is seen in hospitals. The funding available for home health care providers, and the source of that funding, determines who actually will provide the care. The word "nurse" is used commonly in this context and many might assume this means a registered nurse, and that a physician may occasionally visit the home to provide assessment and advice. This is far from the reality. A physician is likely to help in the assessment, but will communicate with a nurse manager/supervisor. That nurse will be a registered nurse and may make occasional visits to the home. Thereafter direct care will be provided by a wide variety of individuals, the most qualified of whom are likely to be Licensed Practical Nurses. More commonly those who provide care in the home are likely to be aides with great variation in their background and training.

Whatever the previous background/training of the individual, specific preparation is required before they can be effective in a new setting such as home care. Such preparation may be supplementary to existing skills as in the case of Registered Nurses or Licensed Practical Nurses, or it may be far more extensive for aides or informal care givers. Whatever the educational level of the individual, the further preparation will include information on technology applied to the home, communication issues, ethics, special situations, and will need to address areas of responsibility, and the risks and joys of working independently. Further consideration would be identifying sources of funding for the training.

An overall definition of home health care has not been developed. It is defined in the negative, as being "not hospital care". In the current rapid development and evolution of home care, a more coherent philosophy of home health care is needed. Some of the barriers to developing a coherent philosophy are the wide range of situations now encompassed by the term 'home health care'. Earlier a description was provided of an individual with severe infection who might have an intravenous cannulla. Another aspect of home health care might be an individual who is near the end of life perhaps from severe cardiovascular or neurological disease, or malignant disease. Another example might be someone with a tracheostomy with a long life expectancy but a need for minute-by-minute meticulous care. Already mentioned are those patients on ventilators who might also require a wide array of medications, and may require specific changes in the treatment from time to time. Thus, with only a few exceptions, care provided in the home encompasses virtually the whole range of care provided in hospital.

Even as the locus of health care is dramatically changing, the broad ethical constructs are being challenged in all settings. In home health care there are new ethical questions, but given the concerns with the existing ethical constructs, bioethicists have explored a variety of approaches. Some have tried to use the principles of health care ethics (autonomy, beneficence, non-maleficence and justice) as a way to approach medical issues in home health care. However while the four principles have been used extensively in acute care, their uniform and exclusive use is being revisited. Some would replace the principles entirely,

while others would supplement them. One commonly suggested or supplementary/alternative approach, particularly suited to home care, is to closely examine the role and significance of relationships in conjunction with the four principles when we try to find an answer to ethical questions. It is very likely that when care is delivered in the home, issues of relationships will predominate, and ideas developed from the four principles will be subordinate.

The Home Health Care Provider

The relationship between care provider and care recipient is a key element in home care. In order to understand this relationship, it is important to examine the reality of both the care provider and the care recipient. Care providers can be divided broadly into two groups. On the one hand there are the unpaid care takers and on the other, those individuals who are being paid to provide home care. The latter group covers a huge range of training and skill sets, from highly trained health care professionals to largely untrained care aides. Although there are a number of issues that are unique to each of these two groups, there are also a number of overlapping considerations. One shared issue is that the relationship through which care is being provided is frequently characterized by vulnerabilities, not only on the part of the recipient, but also on the part of the provider.

Provision of care in the home has traditionally been the role and responsibility of women. This, by and large, continues to be the case as home care providers and care takers are mostly women. Some writers have commented that home care is rooted in the exploitation of women's traditional role as caretakers. One writer noted:

> dependent recipients of care are personally vulnerable to the quality of the caregiving relationship, which in turn is subject to the vicissitudes of fluctuating social and economic policies. Care-providers, for their part, risk being coerced into care taking (particularly by gendered expectations), exploited within the work context, and denied morally acceptable exit options.[i]

According to the above authors, one of the central requirements to creating a morally acceptable caregiving relationship, specifically between a paid home care provider and her patient, is the idea of the care provider being a transparent self; that is, the care giver must faithfully reflect the needs and interests of the cared-for without allowing them to be distorted by her own needs and interests.[ii] Such a relationship is clearly impossible where the care giver must worry about how her own needs are to be met. In a working reality where full time hours are rarely guaranteed, wages are kept very low, benefits often not provided, and the patient's needs often exceed the skill level of the care provider, the paid care provider is simply not in a position to provide a "morally acceptable" level of care. In many instances, home care might be described as one vulnerable individual

caring for another within the home of the receiver. The result of these poor working conditions and not being sufficiently valued is that the health care provider often suffers from burn out, stress, and lowered self-esteem. This in turn results in a significant reduction in the level of care being provided as the focus shifts from "caring about" the patient to a much more mechanical and limited "caring for" the patient.

Although a certain amount of oversight is required, this is complicated by the multitude of agencies involved in providing payment. One of the reasons for oversight is that there is potential for abuse, and a possibility of reduced levels of care when the provider is both overworked (and underpaid) and very far from supervision. This oversight has led to a loss of flexibility. One approach to oversight has been the development of home care checklists, essentially an itemization of steps to complete when providing care. The paid, but only remotely supervised, home health care provider then checks off the items as they are completed. While understandable, relegation of care to items in a checklist does not respect the abilities of the care providers. It limits their full involvement in the care, and turns the provision of care into a mechanical series of steps. This then can lead to loss of empathy in the provider, and brings into the home some measure of the impersonal care that is already seen in the institution, and against which home care is rebelling.

The concept of the transparent self arguably does not apply to the unpaid, informal care giver where the needs, interests, and identity of the care taker are often intimately linked with the care receiver. However, these caretakers subsidize society through their work, and this is often at significant expense and cost to themselves. These individuals often suffer loss of employment and/or set backs in their careers; however, because informal caring work is not recognized as a 'job' there are no safety nets, such as unemployment benefits, to offer any security. Instead, these care givers are left to go through what is often an all consuming, emotionally draining experience with nothing to bridge the transition back to their previous occupations or lives. This clearly places increased stress on the individual, and on each of the complicated and intertwined relationships within the home.

Hence, under the current 'system' of home care there are significant human costs for both the paid and unpaid care providers. Additional research is required in order to determine the impact of sustained care-giving on both unpaid care takers and paid care providers in this context, to determine the effects that poor working conditions are having on the care providers, and to determine what the most effective steps would be to address these issues. These questions often inspire impassioned responses. Some authors have even gone so far as suggesting the following solutions:
- ensure that family care givers are adequately compensated and supported in making the transition both to caretaker, and then in re-establishing aspects of their lives that were impacted by their role as care giver;

- strive to make the long term nursing home care more personal, and therefore a more appealing alternative to home care from the patient perspective;
- ensuring that home care delivery is a not-for-profit undertaking;
- having home care delivery publicly owned; and
- unionization of home care providers.

The first and second suggested solutions are entirely positive and reasonable, and we would support their implementation entirely. Bringing these issues to the public, and having open and frank dialogue with all stakeholders to explore the spectrum of possible solutions and the most effective means of implementing them is an important process. It is not clear that the other suggestions will necessarily lead to improvements in care. Some may be impractical and others may be counterproductive.

Is Home Care all it is cracked up to be?

As alluded to in the introduction, three assumptions underlie the transition from hospital based care to home care, namely that home care is a low-cost alternative to hospital based care, that a comparable standard of care will be delivered in the home as is delivered in the hospitals with similar outcomes, and that patients prefer to receive care and treatment in their homes. Whether these assumptions are in fact an accurate reflection of reality is highly questionable. There is little conclusive evidence that the significant shifting of care from the hospital to the home is a positive move, either economically, or in terms of the quality of care and outcomes experienced by the patient.   Despite the dearth of evidence, this trend of deinstitutionalization of care continues, driven by political motivations, technological advances, and the unchallenged assumption that patients prefer to be treated in the home when possible. The level of acuity is increasing in the hospital and with earlier discharges and fewer hospital beds available, care at home is also increasing in acuity and complexity. Thus more and more people are receiving ever more complex and involved care in the home. Provision of this care is largely by informal care givers who are likely to have little or no formal training. In this way, the move away from institutional care is affecting not only patients but the individuals that care for them, either formally or informally.

Meaning of Home
Another area that needs to be further explored in the home care debate is the impact that providing increasingly complex care in the home is having on the patient and other family members, both in terms of their relationships to each other and in terms of their conceptualization of home generally. With more and more health care being delivered in the home, there is a valid concern that steps be taken to ensure that the meaning of home is not eroded.   The home

environment is not only a dwelling place, but is also intricately connected to one's sense of personal identity, security, and privacy[iii]. These meanings, or connections with home also likely vary with, *inter alia*, class, ethnicity, and family size[iv]. Although like the home, a hospital has certain domestic functions (food, shelter, refuge), it is a place that is generally to be avoided and in which all relationships are dominated and determined by the medical model. Given the significance of place to human identity and existence, Dr. Peter notes that "the experience of receiving and providing health care services cannot be wholly separated from the places in which they are received or provided."[v] Peter suggests human geography and feminist ethics as tools with which to explore and understand the impact of providing care in the home setting. In addition, she comments on the importance of adopting a social justice perspective, as opposed to a market justice perspective. As noted above, what home means for an individual and how it impacts one's identity is likely affected by one's circumstances. It only makes sense to discuss home care in a social justice context, which unlike market justice, takes into account the very important fact that people are differently located and not all on a level playing field financially, socially, or in terms of familial relationships.

The home is made up of a complex network of relationships that impacts the way in which care is delivered and received. Coming into this context, a formal care giver is in a distinctly different situation than she would be within a hospital. One difference is that whereas in the hospital setting, the role of guest is held by the patient, here the roles are reversed and the patient is the host. The care provider is a guest, and as such must seek entry and determine how best to set the professional boundaries. The lack of clarity as to who the client is in the home care context also adds to the complexity of establishing professional boundaries. The presence of the home care worker will have significant implications for everyone involved, for although she will be providing care to the patient, she is also often providing respite and support to the family members.

The decision making process is also different within the home care setting. Determining who ought to be involved in the decision making process is potentially more complicated in the home setting where there are a number of individuals potentially involved with the care of the patient. Even in situations where the patient is competent and able to make the decision, it is likely that other family members will be very involved.

Another question of interest is how, and to what extent, a patient's privacy and autonomy can be protected within the context of home care. Peter comments that "promotion of autonomy of the health care client has little to do with medical decision making, but is more nuanced and concerned with the everyday such as the preservation of privacy."[vi] This reflects the doubt, expressed earlier, that the four principles of health care ethics will be decisive in resolving the ethical issues that arise in home care. Instead, the solutions to such issues are far more likely to arise out of the relationships that already exist within the home.

The intricate relationships that form a household, and through which the family members and the patient identify themselves, need to be appreciated in the home care context—these relationships have the potential to be a source of strength and help to create a positive therapeutic environment in the home, but they also could be a source of incredible stress and conflict for the patient and the caregivers. Further research into the home environment, and how such environment is affected by the infiltration of the medical realm, will be crucial in developing ways to reduce the stress levels of the patient and their informal care givers, and to determine how informal care givers can be effectively supported in a way that will preserve their own health and reduce their stress and anxiety. As was mentioned in the previous section, supporting the informal care givers in such a fashion is crucial to any notion of sustainability of home care.

Complex home health care in children - Locus of decision making

Scientific advances in various areas of medicine, such as perinatal care, have led to increased neonatal survival frequently accompanied by disorders that would not have had time to evolve in the past. Improvements in diagnostic abilities, early clinical care and life-saving technological developments have also led to substantial progress in the care of seriously ill children with life threatening illnesses, often extending their lives significantly. As noted by one writer,
> "this situation brings with it a host of ethical challenges affecting patients, their families, health care professionals and society as a whole. These challenges result from the complexity of care involved, scientific uncertainty as to outcome, lack of medical and social consensus on ethical standards for treatment of some children, inadequate social, emotional, physical and financial resources for the children and their families…"[vii]

Some of the questions that arise within these challenges include determining who are the appropriate decision makers in regards to the care and treatment provided to the child, assessing the proper standard to be applied (or more accurately, determining what is in the best interests of the child), and deciding what externalities are appropriately considered in making such decisions.
The list of potential decision makers is quite extensive, and includes (among others), the patient (where mature minor considerations may be appropriate), the parents, other family members involved with care, the health care professional, government or institutional decision makers (public guardian and trustee, for example, or the courts), and hospital ethics committees. Clearly, the choice of decision maker will affect at least to some degree, the values, concerns, and interests that are considered and which form the foundation for a decision regarding care or treatment. In Canada, significant weight and priority is given to familial privacy and the preservation of parental authority. In contrast, in Europe the health care professional is more heavily involved in each step of the decision

making process. The underlying rationale seems to be that in addition to the their specialized knowledge, trained health care professionals are much less vulnerable to the stress and turmoil of caring for a sick child, than are the child's parents or family members. This approach, although practical on some levels, ignores a wide range of issues that are at play. For example, the health care professional will not be caring for the child in the home, and is likely not fully aware of the constraints imposed by familial relationships, financial restrictions, emotional stability or other aspects of family life that might make caring for a severely disabled child in the home even more stressful than anticipated by those within the institutional setting. Although there may be some question as to whether such externalities (and which ones) are morally relevant to the decision of what is in the best interest of the child, there is no question that practically, such factors do affect the level of care that will be available to the child in the home.

Given the breadth of possible decision makers and approaches, it is vital to ensure that there is a readily available and well established mechanism for dealing with irreconcilable differences of opinion between the potential decision makers. Hospitals often have internal dispute resolution mechanisms, which in these cases would likely involve some form of ethics consultation. Ideally, such matters would be resolved through less formal and minimally adversarial means of mediation and without the necessity of court intervention; however, that mechanism is also available if required.

Some writers have suggested that parents or surrogate decision makers ought to be able to depend on the health care professional to lay out the relevant information (diagnosis, probable and possible outcomes, alternative approaches for treatment and the risks and benefits associated with each) in clear language that they can understand; further, the parents should also be able to request a recommendation, and then be supported in their decision. This, at least theoretically, allows for the best available information from both the physician perspective and the familial perspective to be considered in the decision, and means that the parents are not left to make what can be extremely difficult choices, on their own. However, there are some serious flaws in this approach. Given the breadth and complexity of factors (for example, familial finances, relationships, emotional stability, to name but a few) that come into play when complex health care is transferred to the home, it is practically impossible for the physician to determine all of the information that will be relevant to that particular family and that particular patient. In addition, it is also often extremely difficult for parents to comprehend in any meaningful way the degree of impairment that is involved with a ventilator dependent child, or how this will impact the entire spectrum of their lives, both within and outside the home. Because of these limitations, the physician must provide all the information he or she has any reason to believe will be relevant to the patient and the family, and to lay out the range of medically appropriate options; however, in light of the significant limitations discussed above, it is not appropriate for the physician to provide a

strong, direct recommendation. It is appropriate to indicate preferable options and it is vital to support the parents in their decision.

It is unclear which physician, or physicians, would be the right ones to provide information. A more comprehensive view can be given to the family when a variety of physicians are present, but too many physicians at one meeting may be overwhelming. The issue is important as there has been considerable specialization in physicians, and the physician looking after the child initially is not likely to be the physician providing long term care. At present the dialogue regarding the appropriateness of home care is likely to be led by an intensive care physician, and less likely to be by a physician with training and experience in long term care in the home. The questions that parents ask are likely to focus on the lived experience of having a child who is technology dependent in their home, rather than technical questions on ventilator use, for example. When communicating with families those responsible should be aware of the varieties of expertise available.

An added complicating factor in this discussion, and one which is equally applicable to all home care discussions, is that there is an undeniable double standard between care provided within an institution and care provided within the home. One example is that within a hospital assisted ventilation requires a special unit with specialized health care providers, especially when the patient is a child; however, when this level of care is shifted to the home, the family/informal caregivers are expected to pick up the slack and provide the care. There are also many services and aspects of treatment that are routinely provided within the hospital that are simply not provided within the home. A simple example might be fully funding the ventilator but not funding the disposable supplies which are low-cost on a daily basis but expensive in the long-term. This double standard is a result of downsizing hospitals without providing sufficient resources to the home care sector to pick up the slack.

Complex home health care in children - The meaning of home

As discussed in an earlier section of this paper, one's very sense of identity, privacy and sense of security are intimately connected to one's home environment. This is particularly important in the context of a seriously ill child, for whom the home is often a place of refuge and respite. The complexity of relationships is no less significant in the case of a child patient, either. In fact, in some ways it is more complex than for an adult. In the case of the child home care patient, the household will often include one or both of the parents and the siblings. The stress and intensity of having a seriously ill child at home has serious implications for the development of the other children, as they vie for the attention of parents who are often understandably preoccupied and exhausted. The meaning of home in this context has serious implications for the patient, and for the entire family.   From the patient's perspective, it is important for the care

providers to attempt to strike a balance between providing the treatment needed for the illness, and ensuring that the care provided maintains the security, comfort, reassurance and refuge needed by the child. From the family's perspective, the role of the care provider is to ensure that the parents have the support and reassurance they need to give them some respite and give them some energy to be there for their other children as much as possible, and to give them time for themselves. This again highlights the confusion on the question of who is the client of the paid home health care provider.

Ethical Dimensions of Home Care policies for Children and Youth

As a result of the advances in medical science and technology, there is a growing population of children and youth who need acute care in the home. However, this population does not have the same public voice as adults, which is significant especially in the context of public policy being so influenced by forces such as interest groups. This reality is further exacerbated [or reflected] by the fact that research regarding home care in a pediatric/youth population is at best only in the very early stages.
Reporting on a review of a wide variety of policy documents (including, but in no way limited to, the Kirby and Romanow Reports—as well as submissions to these commissions), certain academics[viii] have noted the following concerns:
1. Health care legislation and programs do not explicitly address the needs of special populations, such as children and youth;
2. The legislation and policy seems to focus on the type of service, with little or no thought/consideration to the population being served;
3. There is no single structure coordinating the home care services for youth; in fact, there is no indication that home care for children and youth is even on the national public policy (health care) radar.

Another difficulty emerging from existing legislation and policy is that although the general position that has been expressed in these documents is that community care is ideal, there is a great deal of uncertainty as to what this in fact means. It is unclear whether the goal of community care is 'care in the community' or 'care by the community'. Even taking the best case scenario and assuming that what we as a society are striving towards is care in the community [ie care in the community with all appropriate support by trained health care providers], this is neither always possible nor ideal.

As discussed in previous sections, the meaning of home is a powerful and important concept; however, on a policy level assuming a certain definition of home excludes certain people from receiving home care. A certain understanding of home [stable, and relatively functional-both in terms of actual physical structure and the relationships therein], and an assumption that the relevant population is fairly independent, seem to be central to the way in which this concept of community care is currently being understood at a policy level.

These conceptualizations, however, do not fit the child population well at all, and exclude a significant portion of the more vulnerable adult population.

It has been argued by some that pediatric home care policy needs to focus on assessing the needs of the child citizen, determining who is responsible for providing their care (society, family etc), balancing parental authority and public duties and ensuring adequate support for services previously provided in the institution setting by health care providers. In response to the question "What ethical approach will facilitate good policy here?", the answer would likely be an ethical approach that is attentive to the moral dimensions of the policy choices and an ethic that is sensitive to the child, but also to the family and other caregivers that are currently being required to provide increasingly technical care for a higher level of patient acuity with only minimal support. Public policy as a moral and ethical endeavor is about both distributive justice and social justice— that is about power, solidarity, and about inclusion, and protection of the vulnerable populations.

Views of home care providers

One presentation was by a group of home care providers, members of an ethics committee. They surveyed their colleagues asking a question about frequent dilemmas faced, where advice was sought and whether or not a consultation service would be useful. The survey was informal, and it would be wrong to give too much detail on the population studied or the numbers of responses but the broad themes identified are certainly of interest. The commonest concerns were about clients living at risk, availability of resources, issues with colleagues, role conflict and confidentiality. Less common but still important issues were end-of-life decisions, abuse of client, abuse of staff, competency issues with clients, issues of equity, issues of guardianship, and sometimes prejudice towards staff. The themes of clients living at risk, issues of guardianship and issues of competency are appropriately considered together. These health care providers were trying to be respectful of the autonomy of the patient receiving care, but concerned that their marginal competence might mean they were at risk. This is clearly a common problem, and in conversation the providers worked hard to reach an amicable solution. Legal measures were used rarely and only when the risk extended to others.

It is not surprising that they were concerned with issues of resources and equity, a theme that appears frequently in this report.

Documentation translated into checklists does not show respect to the care giver. When the employer does not show inherent respect for the care giver, it is not likely that the patient/client will. This is clearly something that managers need to consider very closely when deciding on the details of reporting requirements.

The list of ethical issues perceived by home care workers has little in common with that perceived by care givers in an institutional setting. Two exceptions are end-of-life decision making and confidentiality; however, even with these the nuances are different. In home care, there is much more concern with individuals living at risk, identification and allocation of resources, and dealing with role conflict.

Language

One of the underlying themes that emerges from this report is that in current discussions regarding home care, there is a lack of consistency in language use which further complicates an already complex issue. The use of words such as 'home health care provider', 'client', 'home', and even 'home care' itself, without any clear understanding about what exactly these terms mean within this ever expanding field, is not at all conducive to meaningful or effective discussion. Until this language issue is addressed, any serious attempts to resolve the complex problems plaguing home health care will remain muddied.
Some of the confusion in language is related to historical realities in health care. Until recently physicians were seen as the leaders in health care and would dictate treatment that he (unusual to be she until late in the 20th Century) felt was in the "Best interest" of the "patient". There has been a reaction against this in many different ways. One of the obvious ways has been an enhancement of the autonomy of the patient, and an assertion that the patient should decide what is in their best interest, and absent patient decision making ability, an appropriate surrogate decision maker should make that decision, not the physicians. The word "patient" although grounded in meanings of suffering, became connected in the minds of many with a model of care where the details were dictated by a physician. Thus in many branches of health care, and in some health care disciplines, the word "client" became accepted. It was hoped that this word would be symbolic of the new relationship between the person with illness and the person providing care. There is no doubt that there has been successful transition in the relationship but the change in terminology brings forth new questions.

One obvious new question is determining whether the relationship between health care provider and "client" is in some ways similar to that between a lawyer and "client", or an engineer and a client. The question has been raised that this relationship may still be fundamentally different because of the vulnerability with which people come to need health care. There is rarely a choice to need health care, and therefore dispassionate giving of instructions to the professional does not fit the reality of the dynamic of the relationship between health care provider and the individual suffering. Moreover the choice of options in the health care setting cannot be all encompassing. In any given health care situation there are a limited number of options that are within the scope of the health care practitioner, and which are likely to be effective. In other words the health care

profession will provide the framework in which the individual suffering will make a decision.

A different question is trying to determine who the "client" will be. There has been a glib substitution of client for patient. Yet if we accept that illnesses affect all those intimately connected with the individual suffering, one might argue that the word "client" may be applied to a larger unit than the individual suffering. This concern is emphasized in the home care setting but is not exclusive to that setting. For example let us consider a one-year old child with severe neuromuscular disease dying at home. Present health care providers would assign the word client to the child. Yet any negotiation or discussion of care is with the parent, and it is easy to argue in this setting that the child is a patient, the parent is a client. Beyond childhood, for most of those suffering who are receiving care at home, there is at least one family member and often more involved in their care. In many of these situations the word client might be applied to a family member providing much of the care, or to the family as a whole. Terminology and language does condition how we approach situations, and careful thought is required in how we use words. A whole scale change in terminology is not needed, and indeed may unintentially generate more confusion, but more thought about current usages is required.

Whatever the terminology used, there has been a broad acceptance of a change in the locus of control in health care generally. Again this is more marked when care is delivered in the home, as the control of the health care professional is much less in that situation as it might be in an institution.

The terminology we apply to care givers is also problematic. Given that much of care in the home is delivered by family members, they are clearly part of the care giving team. Some of the terminology used might include family care givers, intimate care giver, and professional care giver. The terminology present on any of these issues is not settled. Throughout this report we have tried to be specific when we talk about family or professional care givers, and are careful to talk about levels of professionalism in the care givers. However the reader will also find examples of our inconsistent use of language

Reflection on Health Care Ethics

The use of the four principles (autonomy, beneficence, non-maleficence and justice) has featured prominently in modern bioethics. The fact that they attract controversy in some circles does not detract from their general usefulness. The principles have sometimes been supplemented in acute care by considering the relationships involved, ideas derived from feminist ethics. In resource allocation, rather than balancing the four principles, the focus is almost exclusively on justice.

How relevant are these same four principles to home care ethics? If they are used, additional questions arise. 'Autonomy' can be regarded as respect for the person. In the home care setting autonomy cannot be so restrictive, and ought to be seen as a wider concept applied to immediate care givers, to all of those living in the home or even to the whole extended family. 'Doing good' is a cliché that many commentators gloss over as being so self evident as to not require any exploration; however, the concept 'doing good' does require expansion in home care. Should we 'do good' only to the patient/client, when our actions might harm intimate family members. Such a balance is not commonly considered in acute care. 'Do no harm', one of the oldest principles of medicine, also needs to be applied in a wider sense in home care. Finally, 'justice' is probably the principle with the most commonality between ethical analysis in the home and in the institution. In acute care, justice is usually looked at in terms of the individual patient or perhaps a group of patients with common interests. It may be applied at different levels in health care organizations when dealing with funding decisions. These various considerations apply when justice is applied in home care, but justice and fairness must be applied to all of the care givers and family members, not just the patient/client.

Ethical analyses in acute settings can be narrow, such as considering whether treatment should be continued or withdrawn. However, the spectrum of ethical issues that arise in the home care setting is much broader. It is more likely that home care will focus on issues of comfort and release of pain, and on ways of helping families gain acceptance of difficult situations. Sometimes the ethical question might be diffuse, such as maintaining family structure and integrity at moments of great stress. In home care, the primary objective of an ethical analysis may be more difficult to identify.

The role of the care providers is more prominent in ethical analyses in the home care setting. Context does fix meaning. In acute care, health care providers have a clear status and position. The status of home care providers is less clear. In extreme cases, in acute care the care provider has been described as "dislocated from the patient who is dislocated from now". Although no one would support this outcome, in acute care it may be possible to function being "dislocated from the patient". This would be an impossible relationship when the care provider is in the home, as they become enmeshed in a network of relationships. This enmeshment is a reality, but home care providers are also responsible to their managers/peers. Determining lines of responsibility can be confusing for a care provider in close and frequent contact with the family, and only infrequent contact with a manager.

Virtue ethics is being revisited and developed further within modern bioethics. Virtue ethics is an important supplement both to the four principles, and to feminist ethics. Yet while it is easy to identify virtues, and somewhat easy to identify a virtuous person, it is not easy to know that a care giver will be virtuous throughout their stay in the home. Helping individual practitioners to develop and

maintain their sense of themselves as virtuous, and realizing that in practice, can be very difficult. There are many pressures facing care givers who are themselves vulnerable. Hence, developing a sense of the 'good' must be a priority for those providing leadership in health care.

Confidentiality is an important derived theme in all areas of health care, and professionals in health care are trained to respect the privacy of patients. However confidentiality can have different implication in different settings The range of information regarded as private and confidential in the home care setting can be much more personal, intimate and detailed than could ever happen in the institutional setting. For example there may be extremely detailed information on relationships within the household, a level of information which will almost never be available in institutional care. However, many home care providers may not be members of a formal health care profession which has a long tradition of respecting patient confidentiality. In other words the need for confidentiality and respect for privacy is very much greater in home care, but understanding its importance may be less than in acute care.

In health care ethics it is recognized that it is unsafe, sometimes dangerous, for information about a patient to be held by only one person such as the physician. Information acquired by the physician, or other health care professionals, is in general shared with the whole team caring for the patient. From time to time managers may also access this information to assure themselves that high quality care is being provided. In general, patients are aware that confidential information is shared by their direct health care providers, but assume that it does not go further. In home care confidential information is also likely to be shared by the whole health care team. In this setting, this team may have very wide membership, and may involve many individuals who are never in the home, and are not in any way known to the patient or family. There are no generally agreed-to limits on how widely information should be shared. Families are not told that much of their personal health information is passed to many health care professionals unknown to them.

What do patients think of ethical principles? Patients/clients will expect that professionals will treat them with respect, avoid harm and try to do good. The patients/clients may also assume that the health care providers will extend these actions to the entire family. They will perceive a need for justice and fairness, but may have difficulty in understanding how that might apply to their particular situation in their home. In institutions, at least superficially, the amount of care delivered to various individual patients can be seen by many within a particular nursing unit. Such transparency cannot occur in the home, and there is no easy way for the patient to see whether or not there is equity.

It is important not to apply ideas of virtue only to the caregiver. There is an idea that there is a 'good' or 'virtuous' patient/client. The virtuous patient wants to maintain their self-respect and a sense of humor, and continue to have respect

for others. We expect a virtuous patient to have courage and perseverance, to mix hope with realism. However, in the home care setting, the patient assumes the role of host which is traditionally held by the professional in the hospital. This role reversal places obstacles in the development in the idea of the virtuous patient in the home.

A coherent philosophy of home care remains elusive. Such a coherent theory may derive from entirely new ideas. However, it is more likely to include concepts derived from the four principles, feminist ethics and virtue ethics, all recast in the light of a new situation.

APPENDIX I

Main Ethical Themes Developed
- Meaning of home and the importance of the relationships therein;
- Supporting the home care provider;
- Meeting standard of care, while not reducing quality of care;
- Double standards between home and hospital;
- Policy considerations;
- Inconsistency of language
- Complex home health care in children
  - Decision making;
  - Meaning of home;
  - Conflict resolution;
  - Role of physician.

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Appendix II

Suggested priorities for research in the ethics of home care:

- Exploring attitudes to home care, long term care and group home care from many perspectives;

- Explore the experience of families who are receiving home care, and include families able to reflect on the experience from previous contact with home care;

- Training needs of home care practitioners

- Analysis of legal issues, such as professional responsibility, role of confidentiality, as well as the implications of changes in the Canada Health Act

- Develop a framework to describe how relationships will evolve, and how home care providers may deal with boundary issues

- Explore confidentiality in detail;

- Explore perceptions of those at points of transition (commonly called discharge planning) to improve decision making, and help all those involved see that there are many relevant perspectives.

ENDNOTES

[i] This comment is taken from the conference abstract provided for Dr. E. Gedge's paper entitled *Dependency Work and Transparent Selves,* at page 70 of the Conference booklet;

[ii] As discussed by Dr. E. Gedge and J. Parks at the CBS Conference, during the presentation of Dr. E. Gedge's paper entitled *Dependency Work and Transparent Selves,* at page 70 of the Conference booklet;

[iii] Williams, A. (2002) *Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space.* Social Science & Medicine. (55:1), p. 141-154;

[iv] *Ibid*

[v] This comment is taken from the conference abstract provided for Dr. E. Peter's Plenary presentation entitled *The uneasy alliance of healthcare and domestic practices: Implications for the ethics of homecare*, at p. 41 of the CBS Conference booklet;

[vi] *Ibid.*

[vii] This comment is taken from the conference abstract provided for Dr. K. Glass' paper entitled *Ethical and Legal Issues in Deciding on Home Ventilation for Children,* at page 72 of the Conference booklet;

[viii] Dr. Peter; Dr. Spalding; Dr. Conrad; Dr. N. Kenny, and Dr. P. McKeever discussed these concerns in their presentation entitled *Ethical Dimensions of Home Care Policies for Children and Youth: New Frontiers in Methods and Ethical Frameworks (Workshop)* at p. 100 of the CBS Conference booklet.