

**A QUALITATIVE LOOK AT THE ETHICAL ISSUES EXPERIENCED BY
PROFESSIONALS PROVIDING HOME AND COMMUNITY BASED
SERVICES TO INDIVIDUALS
WITH HEAD INJURIES**



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Objectives

- To identify the 6 types of ethical dilemmas home and community based therapists experience
- To recognize the role of cognition, the environment, and consumer rights in creating ethical conflicts
- To improve training and supports for home and community based therapists dealing with ethical dilemmas

Research Problem

- **There has been an increase in the number of people with cognitive disabilities being served in their own homes as a result of the Olmstead Decision**
- **The home and community service setting is complex and may create the opportunity for professionals to confront unique ethical dilemmas.**
- **An improved understanding of these experiences will help organizations providing these services to better prepare and support professionals in the field**

The Research Question

- **What are the ethical dilemmas that home and community based staff providing services to individuals with head injuries confront, and how do they go about making decisions when responding to these dilemmas?**

Literature Review

- **General Business Ethics**
- **Ethics related to general healthcare delivery**
- **Bioethics and Behavioral Ethics**
- **Prescriptive literature related to delivery of home based services to the elderly**
- **Literature related to serving individuals with cognitive disabilities**
- **Gap revealed**

Gap

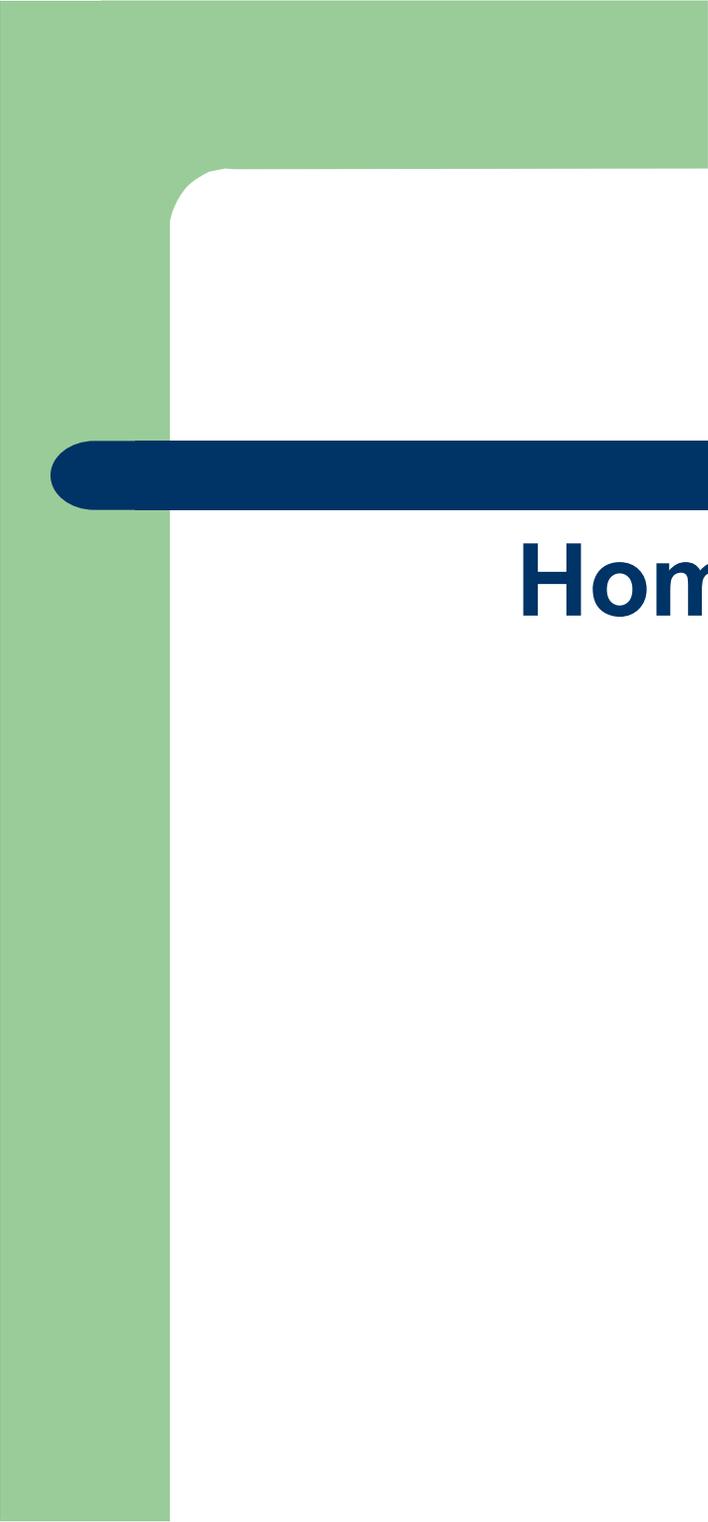
- **Head injury programs are compelled to have a code of ethics and a consumer rights statement, but there is no real research describing how effective this training is once the staff person moves from the training room to the home and community of the people served through the program.**
- **This pointed to the need to conduct a qualitative study to better understand these experiences.**

Participants

- **Professionals providing home and community based brain injury rehabilitation services**
- **Full time, degreed staff providing Cognitive Rehabilitation and Community Integration type services**
- **Two or more years experience**
- **No supervisory responsibilities**
- **All were providing services in the consumer's community of choice. As such, consumers were typically residing in the family home with family members serving as part of the support system.**

Interviews

- **Open ended, in-depth interviews were conducted face- to-face or via Webex.**
- **Interviews were 1-2 hours in length and recorded.**
- **The individual interviews were analyzed for themes.**



Home and Community

vs.

Residential

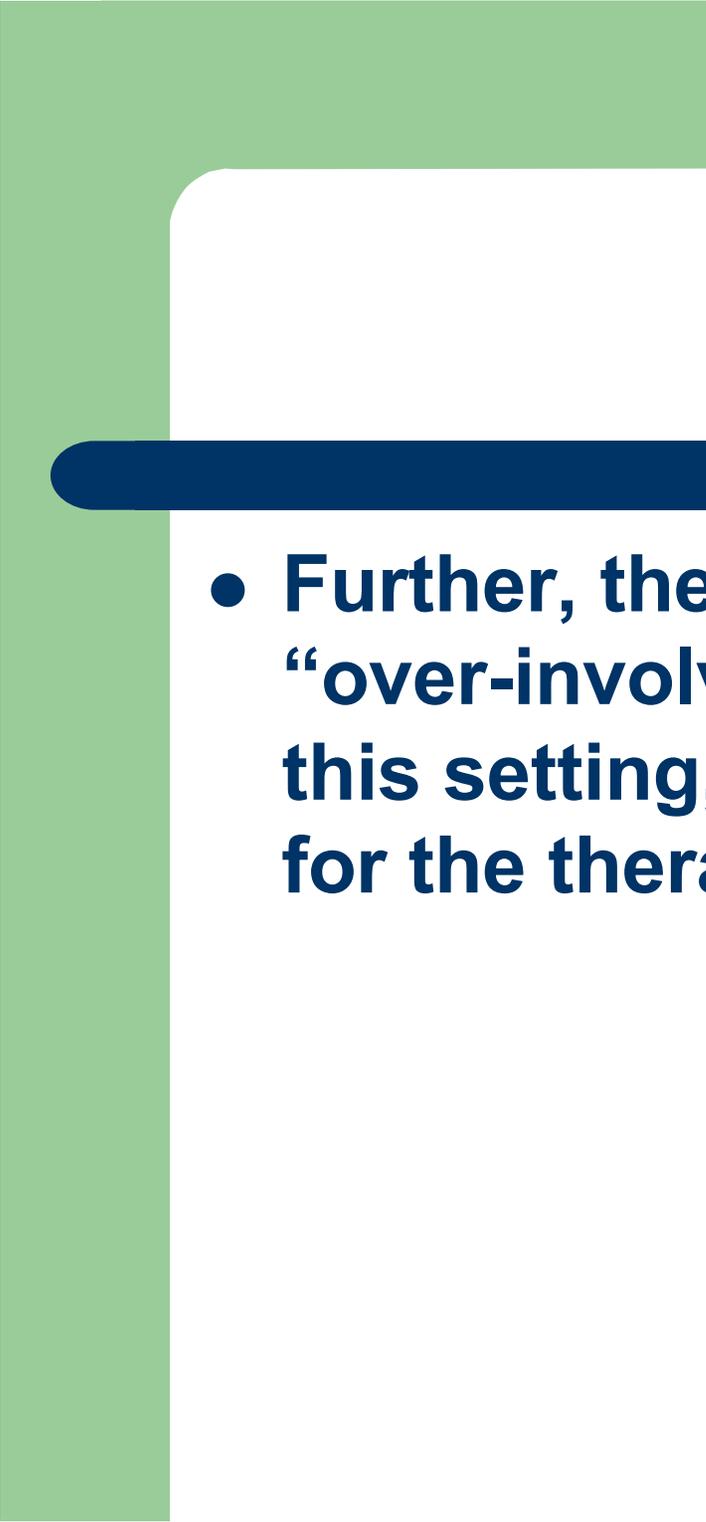
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- **This unique home and community setting demanded closer attention to understand the experience of the therapist and ensure effective support and training of therapists to deal with the unique issues they confront.**
 - **In interviewing these therapists, some themes emerged were commonplace based on the responses to interview questions.**

The Six Themes

- 1) **Boundaries are blurred in this unique setting.**
- 2) **Cognitive issues can contribute to the presence of ethical dilemmas.**
- 3) **Competing priorities create ethical challenges.**
- 4) **Ethical dilemmas arise as related to consumer rights, including autonomy, confidentiality, and management of finances.**
- 5) **Decision-making in response to ethical dilemmas is a personal process that evolves over time.**
- 6) **Support from supervisors is available when dealing with ethical issues, but formal training does not prepare professionals for dealing with ethical issues.**

Theme 1: Boundaries are blurred in this unique setting.

- **The home and community based setting has less structure and control, more family interaction, and limited direct supervision.**
- **One-on-one nature forges a stronger bond between the consumer, family and service provider that can be more intimate than when the consumer is served in a facility based or residential program.**
- **Role confusion is experienced by therapists as professional boundaries were blurred for the consumer and the family.**
- **“Life happens”, so the therapist and consumer may have a well crafted plan that goes out the window when real life issues occur.**

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- **Further, therapists reported families as “over-involved” or “under-involved” in this setting, creating ethical challenges for the therapist.**

Theme 2: Cognitive issues can contribute to the presence of ethical dilemmas.

- **Many consumers experience issues with cognition, commonly in the areas of memory, problem solving, awareness and impulse control.**
- **These cognitive impairments can impact judgement and decision making, setting the stage for ethical dilemmas.**
- **Most consumers have a legal right to make their own decisions.**
- **Staff feel a conflict between protecting the consumer and honoring consumer control.**

Theme 3: Competing priorities create ethical challenges

- **Conflicts between the goals of the consumer, the family, and the organization were common with therapists feeling pulled in different directions.**
- **This resulted in staff feeling as if they must “choose a side”.**
- **Many therapists interviewed reported having to “mediate a lot”.**

Theme 4: Ethical dilemmas arise related to consumer rights, including autonomy, confidentiality, and management of finances.

- **Ethical dilemmas were related primarily to the consumer's right to choose and the professional's desire to act in the consumer's best interests.**
- **They were primarily centered around:**
 - **Confidentiality**
 - **Treatment Planning**
 - **Abuse, neglect and exploitation**

Confidentiality: A Source of Ethical Conflict

#1. Consumers often confided in H & C therapists and requested that they not share information

- All therapists interviewed stated that they would let consumers know that they may have to share information if there was a potential for risk or harm.**
- Therapists felt conflicted about honoring the consumer's request and made the decision based on the potential for harm.**
- Half of the therapists stated that they would not share information with a supervisor unless the situation reached a critical point or might impact their relationship with the consumer.**

Confidentiality: A Source of Ethical Conflict

#2. Family members and other support persons in the home requested information about the consumer.

- Adult consumers have the right to deny family members access to information**
- Therapists may choose to proceed otherwise based on each unique situation.**

Treatment Plan vs. Consumer Desires: A Source of Ethical Conflict

- **Staff were aware of the need to achieve specified outcomes within specific time frames in order to ensure continued funding.**
- **They often felt the need to address issues that were “hot” and helped to avoid potential problems, but felt stressed to meet specific outcomes based on the requirements of contracts with funders.**

Abuse, Neglect and Exploitation: A Source of Ethical Conflict.

- **Therapists' reports of family members mismanaging the consumers' finances were common.**
- **Therapists also frequently witnessed poor living conditions and neglect. At times, abuse was suspected.**
- **Consumers often did not want information shared in any way.**

Theme 5: Decision-making in response to ethical dilemmas is a personal process that evolves over time.

- **Each therapist described a personal journey to establish a style of responding to ethical dilemmas that evolved over time, with consideration of factors that they viewed as important to each situation.**
- **Many participants conveyed a reflective approach that considered the core tenets of Bioethics**
- **All participants described a process that focused on “what’s best for the client” as the priority consideration.**
- **Ethical decision making is dependent on context and the intensity of the risk**

Theme 6: Support from supervisors is available, but...

- **Formal training does not prepare professionals for dealing with ethical issues.**
- **Staff felt supported by direct supervisors, but they acknowledged that they often had to cope with ethical dilemmas on their own, in the moment**
- **Staff reported feeling isolated and disconnected from the organization as a whole, though not from their immediate supervisors.**
- **Experienced therapists felt that new therapists lacked the experience and knowledge to deal with ethical issues effectively.**

Summary of findings

- Therapists reported challenges due to a lack of control and structure within the setting, the blurring of boundaries and role confusion.
- They experienced ethical dilemmas related to autonomy, confidentiality, and management of finances.
- They found it difficult to meet the competing priorities of the consumer, the family and the organization in a manner that promoted consumer choice, beneficence and independence.
- The presence of families further complicated the ethical dilemmas that could be confronted, with issues of power, protection and control.
- The participants described supervisors as supportive and accessible, though they felt ill prepared by their training to deal with the ethical issues confronted.



Implications

Implications: Development of Supports and Training

- Therapists appreciated having a forum to discuss these issues.
- They expressed a willingness to share their experiences with administrators and supervisors within their organizations and to work collaboratively to develop supports and training.
- Improved training has the potential to assist home and community based professionals in feeling more confident in their positions and better able to serve individuals with cognitive disabilities.
- This may result in an improvement in staff retention which can contribute to the organization's financial health.

Implications: The Influence of the Organization

- Therapists used a highly individualized process when facing ethical dilemmas in the field.
- Each participant developed priority values, such as potential for harm and the best interests of the consumer. The priority value appeared to drive the ultimate decision that was made to address the ethical dilemma.
- Company policy was mentioned secondarily in the decision making process.
- It is critical that organizational leaders and direct supervisors are aware of this personal approach, as carefully crafted organizational policies and procedures may have limited influence on the actions of home and community based staff.

Implications: Paternalism ?

- While participants generally stated that their primary consideration in choosing a course of action was what was best for the consumer, there was little discussion about including the consumer in this process.
- None of the participants described a process for viewing the best interest of the consumer from the perspective and values of the consumer.

Implications: Paternalism ?

- **True respect for autonomy considers the best interest based on the consumer's own values. As such, training and supervision for home and community based staff should focus on a conscious process by which professionals make every effort to understand the viewpoint of the consumer, including their goals and personal values.**
- **This process must be a thoughtful one, in which the professional's perceptions and values are set aside in order to identify and respond in a manner that is consistent with the consumer's desires.**

Recommendations

- It may be useful to explore the mechanism by which participants arrive at the determination of the “best interests” of the person served.
- Organizations may benefit from an exploration of the influence of the organization’s culture when the work environment is not contained within the four walls of the organization, but in the homes of consumers.
- It is suggested that organizations develop a survey or a focus group.

Recommendations for Training

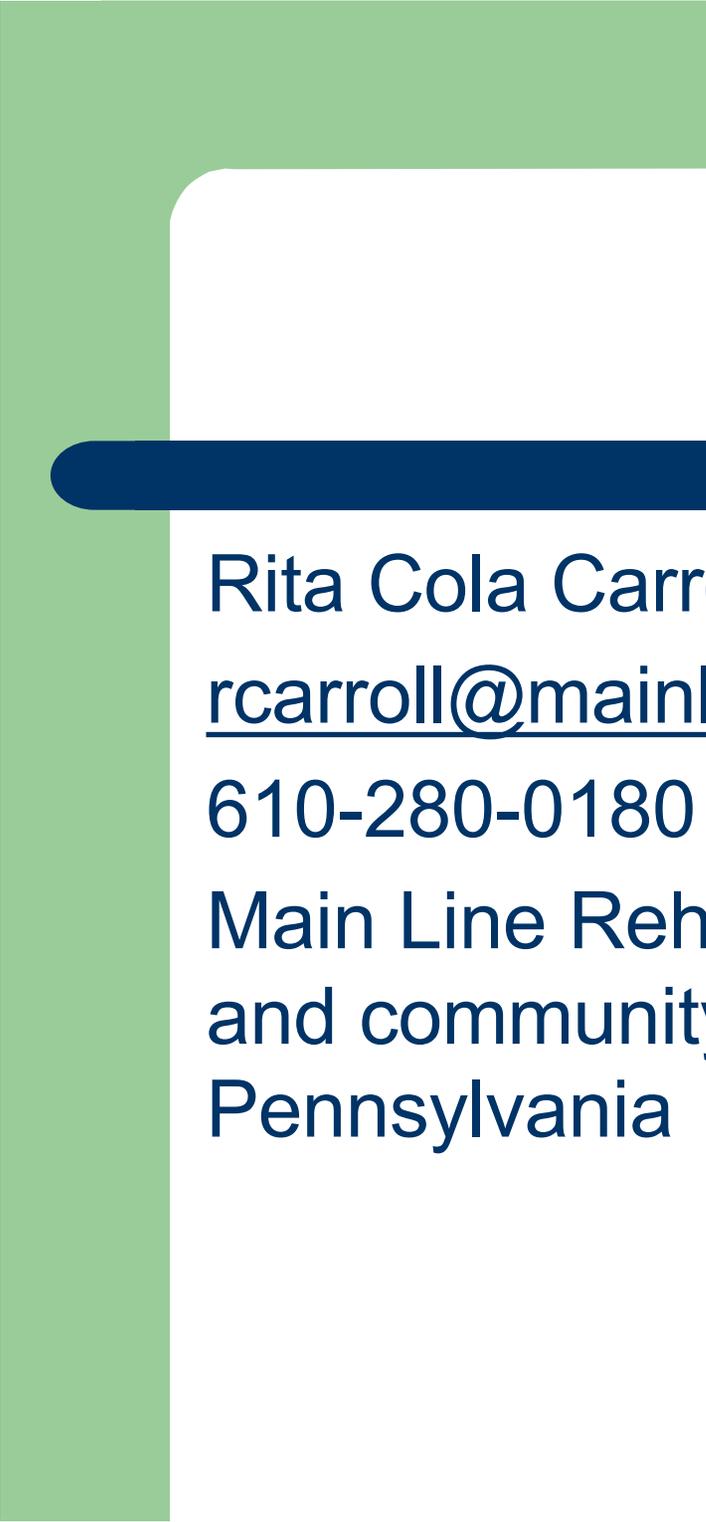
- Therapists in this study felt that scenario based training and role play could help staff feel better prepared and more confident in dealing with the unpredictable nature of ethical dilemmas.
- A model that focuses on rehearsal and practice of responses may provide employees with the tools and skills they need to do the right thing.
- A focus on the actions that result in a moral response to a scenario, as opposed to an application of policies and codes, may enable individuals to craft their personal responses based on positive examples of ethical decisions.
- This approach should be coupled with training that facilitates the therapist's personal exploration of their own values and processes for decision making.

Take Home Messages

- Therapists felt more connected to the people they served, their families and their immediate supervisors and less connected to their organizations.
- With the organization having a distant influence, therapists responded to ethical dilemmas based on their own reflective thought process, and “the best interest” of the person served.
- Paternalism and lack of consideration for ethics policies were evident.
- Perhaps most importantly, the therapists interviewed were dedicated to meeting the needs of people with head injuries, in their own home, so that therapy was immediately relevant and impactful. They can serve as wonderful resources who are willing to actively collaborate in the design of meaningful training.

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