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Experiences of ethical dilemmas in rehabilitation: Swedish occupational therapists' perspectives

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Abstract
The aim of this study was to describe Swedish occupational therapists' experiences of encountering ethical dilemmas in rehabilitation and strategies they used to handle the situations. Twelve occupational therapists who work with adults with developmental disabilities were interviewed using a semi-structured interview design. Data were analysed using qualitative content analysis. The results showed that ethical dilemmas were common in the occupational therapists' daily work within rehabilitation. Many situations that created ethical dilemmas were related to occupational therapists who worked with clients and their relatives, and other healthcare providers. The results showed further that occupational therapists found it difficult to make decisions and to optimize clients' participation in decision-making, to set limits and act professionally, and to best handle the situation for the client and avoid ethical dilemmas. This study indicates the importance of illustrating experiences of ethical dilemmas within occupational therapy praxis and the meaning of discussing ethical dilemmas with different healthcare providers to reach a divided view of the client in order to develop successful and healthy strategies that will optimize the rehabilitation of clients with developmental disabilities.

Key words: *Autonomy, ethical dilemmas, integrity, occupational therapy, participation, professionalism*

Introduction

In Sweden, as in other countries, occupational therapists work on the basis of scientific knowledge and proven experience, to improve the capability of clients to live a worthwhile life in accordance with their desires and requests and in relation to the demands of society. This stresses the importance of ethical knowledge of occupational therapists' work as they are educated and expected to adhere to the values of the occupational therapy profession (1). However, occupational therapists are guided in their daily work by their personal values and beliefs about what is right and good for a client. Such personal beliefs define occupational therapists' sense of morality and influence how they customarily make decisions and react to ethical dilemmas. Although morality refers to an individual's personal set of beliefs and values, the term *ethics* is used to describe the understanding of moral issues from a broader perspective (2). Ethical dilemmas arise from situations that involve conflicting values about what is right or the best course of action. In such situations, a conflict may arise between two or more ethical principles, and each possible solution of the conflict may contain undesirable outcomes for one or more parties involved (3,4).

The ethical principles and rules that commonly guide occupational therapy praxis are *The professional ethical code for occupational therapists* (1), which includes principles, obligations, and guidelines that define responsibilities to achieve high quality in the profession. However, a professional ethical code can never be complete in every situation, and the aim of the Code of Ethics (1) is to be an aid for analysis and a guide in correlation with making ethical decisions by indicating a number of obligations incumbent on occupational therapy. It is not always possible to reconcile these different obligations in a simple way for occupational therapists that makes considerable demands on ethical awareness for occupational

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therapists. The ethical code is in accordance with the International Classification of Functioning, Disability and Health (ICF) (5), which pointed out the correlation between activity, performance, health and prevention measures, and autonomous decision-making. Autonomy refers to respecting the right of all people to make choices and decisions freely based on their own individual values and beliefs, while respect extends to treating all people, such as clients, co-workers, and one's self, and the workplace with a sense of worth (6). The occupational therapist is obliged to respect the rights attributed to clients and other individuals affected by the work of therapists. Obligations must be balanced with one another; however, it may be impossible to unite all different obligations of occupational therapists' work.

During their lifetime, people make more or less autonomous decisions that support their sense of achievement and satisfaction in life. In clients with developmental disabilities, this obligation of autonomy might be reduced, which influences the client's opportunities to achieve independence. Estimating the clients' obligations of autonomy within rehabilitation might be complicated for occupational therapists, when autonomous decisions require a high level of competence in the client. The issues of autonomy might contribute more complexity to clinical decision-making. In situations where different people are responsible for making decisions, occupational therapists have to be aware of and facilitate the client's autonomy, self-determination, and integrity when making decisions about issues in their lives (7). To support decision-making for clients with developmental disabilities as much as possible, occupational therapists should help them become autonomous in performance and in managing their daily lives (8). Other healthcare providers might have another approach in mind, which can negatively affect the client (from an occupational therapy perspective) and thereby create ethical dilemmas for occupational therapists (9,10).

Rehabilitation for people with developmental disabilities is often a long-term relationship between the client and healthcare providers such as occupational therapists, social workers, and the client's relatives. Interventions therefore necessitate cooperation between many persons to assist people with developmental disabilities in managing different life situations. On the other hand, when many persons are involved in decision-making situations, ethical dilemmas might occur because how an individual perceives and reacts to a situation is a highly individualized process and depends on the individual's unique set of beliefs and values. What occupational therapists see as an ethical dilemma may not be seen as troublesome by another professional who is guided by a different set of principles and priorities. There are only a few published studies in the area of occupational therapy (11,12) describing ethical dilemmas; these studies pointed out a medical perspective, including generalized statements and experiences concerning occupational therapists, nurses, and physicians. The results of these studies may for that reason be difficult to apply to the perspective of occupational therapy, within rehabilitation of developmental disabilities. The aim of this study was therefore to describe occupational therapists' experiences of encountering ethical dilemmas in rehabilitation and strategies they used to handle the situations.

Material and method

A qualitative approach was used to gain knowledge of occupational therapists' experience of encountering ethical dilemmas in rehabilitation and strategies they used to handle such situations. Qualitative approaches provide insights from the perspective of the participants (13). Data were collected through semi-structured interviews and were analysed using a qualitative content analysis (14).

Participants

A purposive sample of 12 occupational therapists participated in the study. The inclusion criteria were as follows: the participants 1) were registered occupational therapists, 2) had worked within rehabilitation for adults with developmental disabilities, and 3) had experience of ethical dilemmas. The occupational therapists who participated in the study were responsible for giving technical advice to the municipality's rehabilitation programmes for adults diagnosed with developmental disability and had worked between 3 and 25 years within rehabilitation.

The participating occupational therapists were selected with assistance from heads of six primary healthcare centres in the county council and six rehabilitation units in a municipality in the northern part of Sweden. More than 300 occupational therapists were working during the study (2006). Twenty of them matched the inclusion criteria and were contacted of whom 12 chose to participate in the study. After receiving the participant's permission, the first author telephoned each participant to arrange a time and place for the interview. The participants were guaranteed confidentiality and were informed that they could withdraw from the study at any time. The study was approved by the local ethics committee at Luleå University of Technology.

Data collection

Data were collected with semi-structured interviews by the first author through an interview guide with an outline of topics to be covered to capture the respondent's experiences and perceptions of the topic under study and to collect comparable data (15). This design was chosen to get as enriching and complete data as possible and to give the participants possibilities to speak as specifically as possible about their experiences to clarify what they meant and to ask follow-up questions to answers and stories given. The interviews served to enhance the understanding of the research question, and the comprehensiveness of the data helped to improve the reliability of the findings (16). The first question was a broad one asking the participants to talk about their experience of encountering ethical dilemmas in their rehabilitation work. After that, the interview focused on the following topics: Tell me what positive and negative experiences these meetings brought about. Can you give me examples? Say which strategies you have used to handle the ethical dilemmas. The interviews were tape-recorded, lasting approximately 1 hour each, and were transcribed verbatim.

Analysis

The analysis of the transcripts was undertaken using qualitative content analysis. This method can be described as a process of identifying, coding, and categorizing the primary pattern of the data (14). Qualitative content analysis provides a systematic and objective means to make valid inferences from verbal and written data in order to describe the phenomena being studied. To obtain a sense of the overall data, the authors first read the transcribed interviews independently. Then, the most important decision in the analysis was selecting the meaning units of analysis, which was guided by the research question to be answered. Each meaning unit was condensed, i.e. shortening the meaning unit while still preserving the core (14). In this study, the selected meaning units of analysis were every communicative act where the participants described how they experience encountering ethical dilemmas in rehabilitation and strategies they used to handle such situations. Next, the condensed meaning units were coded and sorted into categories according to similarities and differences in content. The categories were then compared to identify threads of meaning that run through the text on an interpretive level. After the categories were established, both authors once again coded the data independently to refine the categories until consensus was reached.

Results

Results showed that ethical dilemmas were common in the occupational therapists' daily work, and many of the ethical situations were related to the work with clients and their relatives, and other healthcare providers. The occupational therapists found it difficult to make decisions and optimize clients' participation in decision-making, to set limits and act professionally, and to best handle the situation for the client. The results are presented in four categories, illustrated with referenced quotations from the interview texts. The categories were: To strive for client's participation; To meet the client with respect; To set the intervention priority; To be professional in relating to others.

To strive for client's participation

In this category, the occupational therapists describe ethical situations where they had to strive and support the client's participation in the rehabilitation effort. As clients often lacked opportunities to participate in decision-making concerning their rehabilitation, their relatives or other healthcare providers made decisions for them, even in situations when the client was partly able to make his/her own choices. The occupational therapists' strategy to handle the situation in order to avoid an ethical dilemma was to address the questions directly to the client and listen to the client's earlier experiences of participation in decision-making, thereby attempting to find a way to support the client to make his/her own decisions. The other strategy described by the occupational therapists was to visualize alternatives for the client, with pictures or photos, supporting the client to participate in decision-making. The strategies came from the occupational therapists' experience that when client participation occurred by actively making independent choices and when information was made available to the client, ethical dilemmas could be avoided. One occupational therapist said:

> "To really participate, the client has to get the information in such a way that he or she can be participating, otherwise it's a false deliberation."

Occupational therapists described further that they often saw clients in a biomedical or a social culture, where others took care of and compensated for their lack of ability to make decisions. This was experienced in different situations; for example, there was a question concerning transport: Should the client go to work by bus or taxi? Occupational therapists described how if they had a chance to cooperate with the client and could draw attention to the successful performance of an activity, the client's repertoire of

experiences was developed. Otherwise an ethical dilemma occurs because an unsuccessfully performed activity often becomes an unsuccessful new experience for the client and this is a situation occupational therapists wanted to prevent. As one occupational therapist said:

> "Don't you dare get onto the wrong bus; if you do, just once, then you go with taxi service for the disabled and elderly people."

Ethical dilemmas occur in situations when the clients' physical environments changed, i.e. when clients' lifestyles or activities were changed. These ethical dilemmas were often connected with participation, e.g. when clients' physical environments changed, such as when they moved to another type of housing, or when clients cross the line from education to occupation. Without influences from a familiar environment, the client's independence in decision-making and performing activities rapidly changes or becomes reduced. Occupational therapist described how clients often had difficulties in making decisions when they came into a new environment, and when the clients had a good verbal skill they were often valued highly by providers they had not met before, which could create ethical dilemmas regarding decision-making. However, all clients needed support and encouragement in decision-making when the structure in a new environment was being developed. To avoid an ethical dilemma, occupational therapists described how they tried to act as a supervisor, supporting the client in the new environment to make the client independent and able to make his/her own decisions.

To meet the client with respect

In this category, occupational therapists described the importance of meeting the client with respect. They gave examples of situations when the client's right to integrity created ethical dilemmas, such as when they should provide or receive information about clients from others (relatives, social workers, or other healthcare providers). This particular situation created a risk of breaching the client's respect and integrity. Other situations were when occupational therapists were contacted by relatives concerning issues around rehabilitation, without informing the client first. Occupational therapists found it difficult to handle and act in accordance with the question the relatives had asked, without violating the client. To handle this kind of situation, occupational therapists described how they had to find a balance between not harming the client's integrity and listening to the relatives and at the same time showing respect to the client and giving him/her the opportunity to make contact with them by him/herself. One quotation attempts an account:

> "I got the problem explained to me by relatives, but the client hasn't made contact with me. The problem for me will be: How can I know all this about the client? I try to act stupid because what is important is the process and that the daily activities will be all right for the client."

Occupational therapists also faced situations when clients, their relatives, or healthcare providers sometimes did not disclose the clients' limits or their strengths, in an attempt to protect the client. This was apparent in situations when relatives or healthcare providers doubted the client's strengths and wanted to hide the client's limitations. When occupational therapists observed and assessed the client's resources and limits, and let the client and their relatives know that the client had adequate resources, conflicting perspectives created an ethical dilemma. To handle this situation, the occupational therapist had to meet the client with respect, without violating the client's integrity. This was done, for example, by showing the client and his/her relatives a film or photo from the assessment during performance of an activity and thereafter discussing the client's abilities. This act gave occupational therapists the opportunities to avoid an ethical dilemma.

To set the intervention priority

In the rehabilitation of a client, occupational therapists often experienced that they had to prioritize alternative interventions from economic aspects. Sometimes, the client's resources were also not enough to implement an intervention, but relatives demanded that the intervention be carried out. When resources and strategies were weighed against previous technological interventions, the aim was to support the client in enhancing his/her activity pattern. Occupational therapists described that relatives were often prevented from making decisions with regard to economic resources. This involved alternatives that were considered valuable for the client, but unfortunately were not chosen by the occupational therapists. When activity performance was given priority, the client adjusted his/her activity performance, thereby compensating for lack of technological interventions. One quotation follows to illustrate this:

> "Support and assistance to the client is always an alternative in connection with a number of technical interventions. I choose to do it to take care of

> the person's resources, to stabilize the situation even, with the lack of technical interventions."

Clients who asked for special technological interventions such as advanced electric wheelchairs and lifts created ethical dilemmas because clients and relatives often had an opinion contrary to that of the occupational therapist. According to occupational therapists, the clients' resources sometimes do not meet the criteria for the technological intervention and do not correspond to the regulation, i.e. the ethical dilemmas occur when the occupational therapist's knowledge suggested that early intervention might increase the client's need of support for activity performance if he/she received the advice. To handle the situation, occupational therapists resorted to discussing the situation with other occupational therapists in order to get support to prioritize without violating the client. Occupational therapists described further that they felt powerless to resolve the ethical dilemmas in focusing on what was best for the client.

Ethical dilemmas concerning priority also occur according to the client's physical living environment, which was the healthcare provider's work-related environment. Situations arose when occupational therapists and healthcare providers had different experiences in obtaining cooperation to enhance the client's activity performance. The issue boiled down to which comes first: the client's needs or the healthcare provider's needs. Occupational therapists argued from the view of what was best for the clients and suggested that the clients were able to perform an activity with support from healthcare providers without the use of advanced technological interventions. The healthcare providers, on the other hand, argue that they needed advanced technology to support the client's activity performance. These situations were difficult to handle because the client's needs were a priority for the occupational therapists, but the healthcare provider's needs could not be ignored as they had the right to have a good work-related environment. Occupational therapists described how they tried to support and supervise the healthcare providers in their work and at the same time pointed out what was best for the client.

To be professional in relating to others

In this category, occupational therapists described the importance of being professional when dealing with clients and their relatives in the client's natural living environment, to avoid ethical dilemmas. In their work with the client, it was common that social relations develop over time and that they, the occupational therapists, were regarded as a friend instead of a professional. Occupational therapists described being invited to clients' birthday parties, being given gifts, and when they meet the client during their leisure time being invited to follow the client to a café. Occupational therapists found these situations difficult to handle as it was hard to strike a balance between acting professionally and being a private person in a small- or medium-sized community. However, occupational therapists pointed out that it was important to exercise professionalism to do good work with the client, but meeting with clients under these circumstances was often unavoidable and occupational therapists found a solution by informing the client to perceive the occupational therapists as a professional person even in these encounters.

> "We made it clear to each other that when we meet outside work, we just say hello to each other and talk about the weather, nothing else."

Occupational therapists also described the importance of being professional in relation to other healthcare providers because different professionals had different perspectives of what was best for the client. Occupational therapists highly valued, for example, independence for clients with developmental disabilities, while other healthcare providers (e.g. personal assistants), had a dissimilar view of rehabilitation. Occupational therapists felt limited in being professional when other healthcare providers treated the client as being less active in occupational performance. To handle these situations and still be professional, occupational therapists tried to create an awareness of the clients' resources among all the providers involved.

Discussion

The aim of this study was to describe occupational therapists' experiences of encountering ethical dilemmas in rehabilitation and strategies they used to handle such situations. The results showed that ethical dilemmas were common in the occupational therapists' daily work, and that they found these situations difficult to handle because many persons were often involved—the client, their relatives, and other healthcare providers—who often had different views of what was best for the client. Central concepts that emerged in the results were supporting clients' participation in decision-making, respecting clients' integrity, prioritizing interventions and professionalism, which are all important for the successful and healthy rehabilitation of clients with developmental disabilities.

Results showed that occupational therapists had to make difficult ethical decisions regarding participation. Client participation in decision-making depended on his/her awareness of the social environment that supported and fostered participation in making decisions. According to occupational therapy theory (8), participation involves both performance and a subjective meaning of engagement. Participation is then both a personal and a contextual experience and the environment can either enable or restrict participation. The type of participation in which a person will engage is also influenced not only by the individual's unique abilities and limitations but also by motives, roles and habits. Interventions must therefore be adapted individually for each client to encourage participation without creating ethical dilemmas (17). Participation has also an impact on health, and how clients rate their health depends often on their self-perception and support in different activities from persons in their social environment such as relatives and healthcare professionals (5,18). This study shows the importance of not only listening to clients' experiences of participating in decision-making but also how clients with developmental disabilities perceive that participation affects their health. This is not addressed in this study but is an interesting topic for further research.

The results describe how occupational therapists often received information about a client without the client's knowledge. Receiving information concerning another person from relatives or other healthcare providers, without respecting the person's right to integrity and showing respect for the individual, is an important task that occupational therapists have to undertake to avoid ethical dilemmas. Occupational therapists have an obligation to keep information about a client confidential (9). For persons with developmental disabilities, it is common for other persons to represent them in different situations, and they often may give out more information than is needed. However, it is essential to consider the client's integrity and handle information carefully so that the client's privacy not is not violated (17). The results of this study showed that when clients partly lacked the ability to make autonomous decisions, they were represented by their relatives, and it was uncertain whether it was the client's wish or the relatives' demands the occupational therapists were informed about. Berggren (19) stated the importance of respecting a client's autonomy and carefully handling information so as to consider the client's integrity. Persons with increased autonomy easily abandon their own rights to decide as they believe that others have a better sense of what needs they have, which in turn affects their integrity and may create ethical dilemmas for those involved (17).

The occupational therapists in this study described how they tried to find strategies to give their clients opportunities to practise making their own decisions to avoid ethical dilemmas. The issue was especially difficult when occupational therapists identified expectations from relatives or other healthcare providers regarding, for instance, technical interventions. A chosen solution should be based on the preferences and rights of the client involved and should be based on needs and abilities. Using the concept of autonomy can be a way of taking care of a client's integrity because it points out that professionals should have a high level of competence in respect of the client's ability (18,20). To respect a person's autonomy includes the individual having the right to be informed, giving information based on all options and their consequences before decision-making (1,8). The results in this study showed that ethical dilemmas often occurred when many different professionals were involved in the decision-making process. This was especially evident when alternatives were not valued equally by the client and client's relatives and other healthcare providers but a priority had to be set. This is in line with Hansen's (9) and Hasselkus's (3) observations that ethical dilemmas occur within an organization, or in relation to relatives, or in relation to colleagues within other professions, who have different experiences and varying ways of seeing what is best for a client. Russel et al. (18) state the importance of occupational therapists having knowledge about ethical issues, and about how to handle and prioritize interventions. However, *The Professional ethical code for occupational therapists* (1) could be used as a tool because the code includes principles, obligations and guidelines defining responsibilities to achieve a high level of quality in the profession, but it is important to be aware that the code does not resolve individual ethical dilemmas (9).

Moreover, the results in this study showed limits between occupational therapists' professional and the client's private sphere. Occupational therapists described how it was difficult to avoid social get-togethers with clients and relatives. According to Scopelleti et al. (21), it is known that ethical dilemmas concerning professionalism and privacy occur when occupational therapists work closely with clients in their natural living environment. The border between friendship and doing professional work in a client's home could be difficult as being received as a friend makes it especially difficult to begin rehabilitation and assert professional standards (10). However, both parties (the client and the occupational therapist) should agree that the relationship between them is

first and foremost professional (22). Regarding the occupational therapist and client relationships, the results in this study show that occupational therapists found it difficult to achieve the right balance between professionalism and benevolence in many social situations. It was difficult for occupational therapists to reason rationally, with the client and probably also to themselves, with regard to *The professional ethical code for occupational therapists* (1). Meeting a client at the clinic is often easier as the meeting takes place in a professional environment. Nevertheless, the occupational therapist had to be aware that ethical dilemmas in this kind of situations include the client's autonomy with a risk of paternalism as regards professionalism (10).

To set the intervention priority and discuss the economics involved in rehabilitation and to assess who is responsible (e.g. municipality or county council or other healthcare providers) was important for the occupational therapists in this study. Russel et al. (18) described occupational therapists' dilemmas in choosing between abandoning professional knowledge to grant clients' wishes for interventions, versus protecting guiding principles in the organization. Occupational therapists attempted to make decisions about interventions that satisfied clients, relatives, and other healthcare providers. Tamm (10) stated that it is important to handle ethical situations where clients, relatives, and healthcare providers are involved in the most professional manner to reach the highest good for clients despite economic aspects.

Methodological considerations

The strength of this study is the insider perspective, i.e. the participants themselves described their experiences of handling ethical dilemmas in praxis. The design of the study, a qualitative interview design, optimizes understanding of the complexities of the research question. Strategies used to enhance the credibility of the study were used in the interview process through the interview guide and follow-up questions. The use of quotations from the interview text was also a strategy to enhance credibility. To enhance dependability and conformability, the methods of data collection and analysis were described in detail and the analysis was done separately by the two authors. However, the results of this study cannot be generalized, as this is not the goal of qualitative research. Instead, the results can be inferred in similar situations if these are modified to comply with the context (13). Because this study was carried out with occupational therapists who work with clients with developmental disabilities, in order to address the limitations of this study it would be interesting to investigate occupational therapists working with other clients to see if they experience similar ethical dilemmas.

Conclusion

Ethical dilemmas are common in occupational therapists' daily work and they experienced difficulties in making decisions and optimizing clients' participation in decision-making, and in acting professionally to respect the clients' integrity, their relatives' wishes, and other healthcare providers.

Clinical implications

This study stresses the importance of illustrating experiences of ethical dilemmas within occupational therapy praxis and of discussing ethical dilemmas with different healthcare providers in order to reach a divided view of the client to develop successful and healthy strategies that will optimize rehabilitation for clients with developmental disabilities. Occupational therapists also have a specific task to identify problems in the environment and improve the reciprocal relationships between the client and the environment (both the physical and the social environment) and find strategies to enable clients and their relatives to participate in decision-making in order to avoid ethical dilemmas.

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