Performing Bimanual Activities: The Experiences of Young Persons With Hemiplegic Cerebral Palsy

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This qualitative research study was designed to explore and describe the process of planning and performing bimanual activities in young persons with hemiplegic cerebral palsy. Interviews with 10 persons individually and four persons in a focus group provided rich information about their reasoning when confronting problems as well as insight into how they view their situations. The data were analyzed using a comparative method. The findings show that the participants had to make conscious choices about what would be the most effective strategies to use for carrying out activities. The choices involved weighing different options to find the least negative alternative. Even when able to find alternative strategies for performing the activity, the participants were often dissatisfied with negative consequences related to the strategy. Examples of such negative consequences could be, for example, that they would have to accept a need for extra time, planning, or concentration, to perform desired activities. When selecting a strategy it was thus favorable to have a repertoire of strategies from which to choose. In conclusion, the planning and performing of bimanual activities turned out to be a complex process influenced by a range of factors both internal and external to the person.


Persons with hemiplegic cerebral palsy encounter many practical obstacles in their daily lives because of decreased function in one arm and leg. The neurological symptoms are spasticity, paresis, sensory dysfunction, and coordination difficulties, all of which make it more or less difficult to control the arm, hand, or leg movement adequately (Eliasson, Gordon, & Forssberg, 1991, 1992; Uvebrant, 1988). In addition, difficulties performing opposite movements with the two hands at the same time (mirror movements) are often experienced (Khutz-Buschbeck, Krumlinde Sundholm, Eliasson, & Forssberg, 2000). Posture is altered, with the elbow and wrist often being flexed, the forearm pronated, and the fingers more or less flexed into the hand on the impaired side (Szabo & Gelberman, 1985).

The basic problems of hemiplegic hand function have been fairly well-described and explored. However, the consequences of this dysfunction on daily life have yet to be described thoroughly. Success in daily activities can be related to the match between the capabilities of the person and the demands that the activity and the environment impose on the person. When the demands exceed the capability, a discrepancy in task performance occurs (Holm, Rogers, & Stone, 1998). Compared to other subgroups, persons with hemiplegic cerebral palsy might be considered to have a mild handicap (Lepage, Noreau, Bernard, & Fougeryrollas, 1998) and from clinical experience we know that many are fully integrated in society, following regular education, etc. The societal demands are essentially the same as for nondisabled people. Thus it can be assumed that for persons with hemiplegic cerebral palsy, societal integration creates certain demands and
expected in terms of performance. How this potential conflict between high demands and lowered capability is solved, has not—as far as we know—been described.

Occupation is more than just doing, it is also a way to master the environment and simultaneously develop and express oneself and create an identity (Christiansen, 1999; Reilly, 1962). Occupational performance is a process in which the human system, the task, and the environment contribute to the assembly of behavior. This process has a fluid and improvisational character (Kielhofner, 1995). The behavior is considered to be functional if the person–environment interactions enable people to achieve goals that correspond to their views on quality of life (Holm et al., 1998). A socially competent performance, however, requires more than just performing the task, it also involves fulfilling social expectations on how the task should be performed. Performing is thus a way to communicate oneself to others (Goffman, 1963). Consequently, occupational performance has the dual aim of achievement of results and of performing competently within social expectations.

Persons with hemiplegic cerebral palsy often receive occupational therapy intervention. Intervention by an occupational therapist is focused on the area where the task–environmental demands are greater than the person's capabilities (Barrett & Kielhofner, 1998). A wide range of intervention methods are used, with some addressing the upper-extremity dysfunction itself and others the consequences it yields in the everyday life of the individual concerned. According to Fisher (1998), enhancing the use of compensatory strategies is an important aspect in the occupational therapy intervention. Today there is—to our knowledge—no description of how persons with hemiplegic cerebral palsy carry out activities or how they solve their occupational problems. Such knowledge might strengthen the ability of the occupational therapist to help clients find efficient alternative strategies for solving problems in everyday life. McCuaig and Frank (1991) agree that there is a need for studies that describe patterns of adaptation by persons with disabilities. The aim of this study therefore is to explore and describe the process of planning and performing bimanual activities in young persons with hemiplegic cerebral palsy.

**Method**

This study originates from an unexpected finding in a former study, designed to describe activity pattern following upper-extremity surgery by people with hemiplegic cerebral palsy (Sköld, Ekholm, & Eliasson, 1999; Sköld, Josephsson, Fittinghoff, & Eliasson, 2003). Analyzing those data, we found that along with the descriptions of how they dealt with practical problems before and after surgery, the participants described a general dissatisfaction with their options for carrying out activities. Further analysis revealed that the use of different strategies for performing activities reflected a complex process of decision making involving factors related to both the person and the person's surroundings. In order to further explore the conditions for this process of choosing strategies for activity performance, we collected additional data using a focus group method (Krueger & Casey, 2000; Morgan, 1997). The study reported here included analysis of interviews from the former study plus data from the focus group session.

The local ethics committee reviewed and approved the study proposal. The participants were informed about the intended use of the data and told that they could withdraw from the study whenever they wished. To protect the participants' confidentiality, all names have been replaced with pseudonyms.

**Participants**

The criteria for participant selection in the initial interview data collection had been formed with the aim to describe activity patterns in relation to upper-extremity surgery. The criteria were: having hemiplegic cerebral palsy, attending regular education at the time of surgery, and having had upper-extremity surgery at least 5 years ago. Following these criteria, the participants were picked out from the surgeon's records of previous patients according to date of surgery. Written invitations describing the research were sent to the families. One week later a follow-up telephone call was made to ask for participation. One person declined to participate in the study and was therefore replaced by the next person on the list. Ten persons 12 to 24 years of age (one male, nine females) agreed to participate and were interviewed individually. Five of the participants came with a parent and the parent was then invited to take part in the interview.

The more exploratory nature of the additional data collection (focus group) caused us to use a more purposive approach to identifying participants for the focus group. Apart from having hemiplegic cerebral palsy and attending or having attended regular education, the informants needed to be able to generate a rich body of information about their own experience of solving problems related to bimanual activities in different settings. We therefore asked local occupational therapists to suggest candidates for the interview considering these criteria (Krueger & Casey, 2000). The suggested participants were given a letter of invitation, describing the purpose of the focus group, by their local occupational therapist and asked for agreement for the researcher to call them and ask for participation. Four per-
The interviews—both individual and focus group—took place in a hospital. The interviewer was an occupational therapist (the first author), experienced in the area of children’s habilitation and hand rehabilitation, who had not previously met the participants. In the first data collection, the interviews were conducted individually, in conjunction with an assessment regarding the study on upper-extremity surgery (Sköld et al., 1999). For practical reasons, the interview with one participant was partially conducted over the telephone.

The aim of the first interviews was to find out how each participant practically dealt with problems related to the reduced function of the hand. The interviews were semi-structured and an interview guide was used (Bogdan & Biklen, 2003; Patton, 1986). A pilot interview was made with an 18-year-old girl with hemiplegic cerebral palsy and the interview guide was thereafter revised. The interview guide consisted of broad questions, allowing the interviewee to focus on a subject area while maintaining freedom to word the questions appropriately for each participant and build conversation spontaneously. The pilot interview gave us information on typical activities that might be difficult to manage for someone with a hemiplegic cerebral palsy. We asked the participants to describe how they performed these activities. The activities in question were: picking up groceries and putting them into a basket, eating a hot dog and drinking a can of Coke® together while standing, carrying full and open bottles, folding a piece of paper and putting it into an envelope, holding a banana and peeling the first strip, and eating with a knife and fork. Since habitual activities might be partly autonomous behavior (Kielhofner, 2002), during the interview, the participants were offered the opportunity to handle the objects used in the above mentioned activities. The purpose was not to observe the action, but to facilitate the participants ability to accurately describe their ordinary performance. The same activities and objects were used for all participants. Thereafter, the participants were asked about situations where the use of the affected hand was avoided as well as activities that they were unable to perform. The individual interviews ranged from 1/2 to 2 hours.

The knowledge acquired through the individual interview analysis was used when planning the semistructured interview guide used for the focus group. The main emphasis by the focus group interviewer was on the reasoning employed when choosing strategies, rather than on strategies per se, and on how the participants themselves viewed their choices. This new emphasis reflected a change in the authors’ assumptions, based on knowledge gained in the first data collection, namely that the process of choosing strategies for occupational performance is decided by a range of factors, internal as well as external to the person. In the second data collection we therefore aimed at gaining information that would complement the data from the first data collection. The focus group interview lasted for 2 hours. All interviews were tape recorded with the participants’ permission and transcribed verbatim by the interviewer.

Data Analysis

Data analysis was guided by a comparative method described by Bogdan and Bilken (2003). The process of analysis started with reading and coding the transcripts to define the main ideas discussed in the interviews. All authors thoroughly read the transcripts to gain an overall sense of the content. The ideas were discussed in relation to how young people with hemiplegic cerebral palsy approach occupational problems so that the authors could agree on what was relevant to the study. In the second step, coding, the first author developed a detailed coding scheme. The codes were developed by identifying in each text part what the participants were talking about. The coding scheme was shared and discussed with the other authors for feedback, which resulted in minor changes. Alternative ways of understanding data were sought by consequently assessing if there might be more than one way to understand the text, and the same part of text could be assigned to more than one code. At this stage, the coding scheme consisted of 19 codes with 76 subcodes (the subcodes represented variations on a code) grouped according to nine categories related to the purpose of the study. The following nine coding categories were defined: specific strategies related to hand use, specific strategies related to other parts of the body, strategies related to the object, strategies related to interaction with other people, strategies that limit the performance, changing strategy, consequences from using a strategy, determinants of strategy selection, and feelings and experiences related to the use of strategies. Each section of text related to a certain code was identified and brought together so that all parts of data relevant to the purpose of the study could be read according to the codes and serve as a background for further analysis.

The third step involved describing the findings by organizing them into a coherent and meaningful whole.
Whereas the sorting of the data into codes had given a structured, descriptive understanding of the data, the third step of the analysis involved analysing similarities and differences between individuals. This comparison led to questions such as “How can we understand that one girl likes to use both hands, while another is very cautious to hide her arm?” We found the answer to this in parts of the text where the two girls described how they perceived that others view them and their disability. This way of working with data yielded a new understanding. We found that the way of using various strategies for activity performance could only be understood when experiences, feelings, and values of the individual as well as the environment in the specific situation, were considered. Based on this new understanding, data were organized into two main themes with nine sub-themes.

Findings

Two main themes emerged from the data analysis. The first main theme was *The dilemma of choosing among various strategy options*. This theme included the subthemes of (1) estimating the feasibility of success, (2) estimating social aspects, and (3) estimating personal aspects. The second main theme was *Some consequences will have to be tolerated*. This theme included the subthemes of (1) planning, (2) taking extra time, (3) paying extra attention, (4) increasing the workload on the rest of the body, (5) limiting choice of task or task performance, and (6) the need for a repertoire of strategies.

**The Dilemma of Choosing Among Various Strategy Options**

The participants described a number of different strategies used for approaching activities they could not perform in a standard way due to their decreased hand function. We were surprised, however, to learn that the strategies were not always presented as positive options. Rather the participants often described the strategies as something negative, something they resorted to when they could not perform the activity in a standard way. It seemed that whatever strategy participants chose, the strategies had some negative consequences that required consideration. The following story, told by Sandra, illustrates her dilemma:

In school I am very…that is, my friend thinks I am very, very lazy. I think that’s what irritates her most. Because I can butter my bread and she knows I can. But anyway, at school I ask her if she can do it for me, or one of my other friends, but she says “You can do it.” “But it…there are about 20 people coming to butter bread at the same time and I need a lot of space. I can’t hold my bread in my hand and spread [the butter]. I have to put the bread down and I need a lot of space….You see? And then…then I don’t take any bread. But if she’s going to have some bread, I ask “Could you do one for me too?”….That is the way it is. She thinks that I… I know how to [butter bread] but I get so stressed. I really need a lot of space. It takes time and I get butter all over my fingers. It takes time to butter the bread. It is possible, but it takes time.

The story of Sandra helps us understand that the various strategies she has to choose from all have some negative consequences. The first strategy requires extra time and space and would also result in getting butter on her hands, the second strategy, asking for help, would result in a conflict with her friend, and the third strategy would result in not having any bread at all. Since none of the strategies offers an ideal solution, this situation involves weighing all options to choose the lesser evil. Sandra’s dilemma reflects the complexity of the process of choosing strategies for activity performance. Based on the entire data collection, we found the following factors to influence the choice of strategy.

**Estimating the Feasibility of Success**

The most obvious factor that the participants had to take into consideration when choosing strategy was the match between their own ability and the demands of the task. Negotiating the intersection between ability and task demands became evident in situations where an increased demand of the task led to a change in the performance strategy. For example, in a shop, the participants might hold the basket with their affected hand to enable them to select groceries with the noninvolved hand. However, if the basket grew heavy the strategy had to be changed. Then the basket had to be carried in the noninvolved hand (thus hindering the use of that hand for selecting groceries). Sometimes the intersection between the task demands and ability was not discovered until the ability limit was exceeded, which resulted in some sort of failure. Sandra described how she usually opens a banana with only one hand by holding it by the stem and using a rapid whipping action so that the stem breaks and the skin opens. But she remarked that “sometimes one was unlucky, one pulled too hard so it [the banana] fell …” In the experience of other participants, cutting food with both hands might result in the food slipping off the plate. The point of intersection between ability and task demands could also be intentionally challenged in order to improve the person’s ability, even if this could evoke a conflict between the wish to try a more advanced strategy and the risk of failure. Helene expressed her feelings about this situation as follows: “One should actually dare to try to take the plate but at the same time one thinks ‘now I’m going to drop it’ and then one doesn’t dare try….I don’t always trust my own ability.” She went on to explain that
the fear of failure was particularly accentuated when handling objects belonging to others due to the risk for breakage. A safer strategy would therefore more likely be used in those situations than when handling one’s own objects.

The effectiveness of performance could be improved either by using a strategy involving both hands or a strategy involving only the noninvolved hand. Helene liked using both hands because “the movements are always better if I can...use two hands, that is, if I can use a counterforce...” Sally described how she prefers to move a chair with two hands instead of one: “It works more easily and smoothly.” Using the noninvolved hand was however more commonly regarded as the more efficient strategy. Several participants remarked that if possible, only the noninvolved hand would be used and the other hand was used only when necessary.

Estimating Social Aspects

Relationships with other people could influence the choice of strategy. The participants’ stories reflected that they would compare their own behavior to that of people without decreased hand function and the choice of strategy seemed often related to a desire to appear “normal.” In front of other people, the participants would either use their affected hand more, in order to appear bimanual, or avoid the use of their affected hand, in order to conceal it. For example, some participants used both hands when eating at a dinner party although they did not do this at home; Beata did this even though it would hurt since her arm got tense. Helene said, “If...there are many people, then I want to use both hands.” Sally, 16 years of age, reasoned in a different way. She said, “People may look at me in a strange way.” She therefore avoided strategies where her decreased hand function would become apparent. She explained she would try to disguise her arm when performing an activity. Helene, 20 years old, remembered her efforts to hide her impaired arm during her teenage years and said, “That was the worst time of my life.” Nowadays she finds it easier to show herself the way she is: “I would never be ashamed.”

The social situation itself could also make it more difficult for the participants to use both hands in task performance. The perceived expectations of other people imposed a stress that influenced the decision about which strategy to use. Helene exemplified this: “…If people don’t know me and I am about to [do something]...it takes more time, then I might get stressed and then I choose to use my right [noninvolved] hand.” How others react to the use of a strategy seemed to be of great importance. Helene described how a stranger reacted to her strategy of using her mouth for holding:

When I was younger I used my mouth all the time. I learned to stop using my mouth once when I went to take some gloves from my pocket and I had a bus ticket...and the bus driver said to me: ‘Do you think I’m going to touch that ticket now? How disgusting!’ It was as if someone had slapped my hand.”

The participants described how asking for help could be a way of managing challenging activities. However, data analysis revealed conflicting feelings on this matter. Asking for help could be viewed as something positive. Helene, for example, would take help from her friends when carrying a tray: “Sometimes it takes a lot of time to get to the table but then I usually get assistance from one of my friends, ‘Please take this glass,’ because even if they only take the glass, that is what I find most difficult.” Asking for help might however also conflict with a wish for independence. When talking about buttoning her trousers, for example, Sandra said, “…I’d rather sit and struggle than ask for help. You feel like...you’re 14 years old and you have to ask someone for help...it’s kind of embarrassing…” Some of the participants described feeling angry or insulted if they were offered help. Accepting help could also interfere with getting the desired result. Sandra was always dissatisfied when her mother helped her with her hair: “My mother always did it in the wrong way, I thought. It was always too tight, too far forward or too far back, too lumpy…” Asking unknown people for help was mostly described as something one tried to avoid. Helene accentuated this choice by first saying “I always ask [for help]” and then correcting herself: “I usually give [new] acquaintances a week [before explaining about the disability] so that they can focus on other things than that. Because if I do [ask for help] immediately...then there will be too much ‘Oh shall I help you?’”

Estimating Personal Aspects

Many of the considerations for choosing strategies were related to other people or to the object; personal preferences however were also taken into consideration. For example, the use of the affected hand could influence the muscle tension in that hand. Both Helene and Beata found that using their affected arm influenced their muscle tone. Beata related this to situations where she stretched out her arm, for example when she tried to reach for something in the shopping cart, then the muscle tonus was diminished. She could, however, also experience the opposite: more demanding situations, like involving her affected hand when cutting food, increased the muscle tension. Another aspect reported by one participant was a personal wish to use her affected hand and arm. Helene explained that she liked to use strategies involving her affected hand: “For my self-confidence. I think it’s fun when I get this feeling of using both [hands].” She was rather annoyed with herself
for not using her affected arm more than she did. She
described how, for example, she would lift a cup with her
affected hand and then, halfway to her mouth, she would
automatically change hands. This she found both irritating
and confusing: "Why? When I got so far, why don’t I do
what I should…Why do I often change hands?...I don’t
understand why I do it, I can’t explain.” This personal wish
to use the affected hand was not expressed by any of the
other participants, and indeed, a rather contradictory view
was described by Beata, who generally disliked both using
and talking about her hand, and by Sally, who preferred to
keep her affected hand passive.

Some Consequences Will Have To Be Tolerated

The second major theme uncovered in the analysis revealed
that, often, the situation of choosing a strategy did not offer
any ideal options. Instead, most strategies had some nega-
tive consequences, which could not be avoided but had to
be tolerated.

Planning

The participants described how they needed to consciously
plan their performance of activities to avoid undesirable
outcomes. One example of this was planning the order in
which different tasks in an activity would take place. When
talking about having a Coke and a hot dog while standing,
Sandra said, “I don’t open the Coke first because then I will
spill it.” Another example was to be prepared to manage
unexpected demands by deliberately keeping the nonin-
volved hand free. This could make it necessary to carry
objects (like a basket or some books) on the affected arm,
even though this was more difficult than carrying on the
other arm. Planning could also involve certain objects that
would facilitate performance. Tina described how she
would buy elastic shoelaces that don’t require tying and
Anne used to choose trousers and shirts that button from
the left to the right thus enabling her to use her left (non-
involved) hand. A few technical aids or adaptations were
mentioned by participants. Helene, however, indicated that
using technical aids might require too much planning.
When the focus group was discussing that lids for the cup
are no longer handed out at McDonald’s, someone suggest-
ed that one might bring a lid. Helene joked: “Today I’m
going to McDonald’s so I have to bring a lid.”

Taking Extra Time

The frustration associated with the use of various strategies
was sometimes related to the time needed for the perfor-
man ce of certain activities. It was often necessary to change
hand roles during the activity, which was time-consuming
and led to discontinuity in performing the action. So, for
example, when zipping up a jacket it could be necessary to
start pulling with the affected hand while the noninvolved
hand stabilized, and then halfway up change hands so that
the noninvolved hand would pull and the other hand
would hold. Helene commented on this: “The movement
doesn’t become automatic, but first I insert [one part of the
zip in the other], then I stop in that position and then I
pull.” Jenny gave another example, saying: “If I have a bot-
tle in this [the noninvolved] hand and I am to receive a
plate full of food in the left [affected] hand…that wouldn’t
work, so I have to put the bottle down and change hands
and put the bottle in the left hand or something.” Several
participants also explained that when eating, they could not
use the knife in the right hand and the fork in the left hand
all through the meal, which is typical behavior in Sweden.
Instead they had to change the cutlery between one hand
and the other several times since the noninvolved hand
must be used both to bring the fork to the mouth and to
cut with the knife. When it came to activities where the
affected hand could not assist at all, the tasks had to be done
in several steps instead of alternating between hands. For
example, when pouring a glass of water from the tap, it
might be necessary to first pick up the glass, then to put it
down to switch on the tap, then pick it up again to fill it
with water, then put it down to be able to switch the tap off,
and then pick it up again to drink. In the same way, the
basket might be held in the noninvolved hand when shopping,
but each time an object was to be selected from the
shelf, the basket would have to be put down to free up the
noninvolved hand.

It might also be necessary to repeat one sequence of the
activity because of ineffective performance. Sandra
described her trouble when using a hair dryer. Holding the
hair dryer with the noninvolved hand, but being unable to
feel the wetness in her hair with the other hand, she had to
repeat the procedure of blowing her hair, putting down the
hair dryer, feeling her hair with the noninvolved hand and
then, if it was still wet, she would start all over again. It was
a similar procedure when rinsing the shampoo from her
hair using the handheld shower: “I thought that ‘now’ it
would be okay, I turned off [the shower], I felt my hair, but
no, the shampoo was still there. I just stood there and took
a chance that it would be washed out by itself, I didn't
rub…”

Paying Extra Attention

The analysis showed that strategies that included the use of
the affected hand often demanded extra attention for the
performance of a particular movement. Helene said:

I notice that there is such a great difference between me
and my friends, that I need a totally different level of con-
centation than them, just to perform a simple movement because to them it is an unconscious movement....I have to help my hand like this: “grab the drawer” and “pull out the drawer.”

If the person did not concentrate on the affected hand, the object was either dropped or forgotten in the hand or, if it was a soft object, squeezed too hard. Sandra described how she once took out her chewing gum and put it in her affected hand. She then forgot that she was holding it until her grandmother took her by the hand. It could also be necessary to use sight to compensate for the poor awareness of the hand. Jenny was aware that when carrying, for example, two bottles she must keep her eye on the bottle held by her affected hand, otherwise she might spill it. “If both bottles are full I make sure I hold first one up and then I take the other, but I need to keep my eyes on this one [the bottle held in the affected hand] so that it doesn’t spill,” she said.

**Increasing the Workload on the Rest of the Body**

The strategies applied often raised the demands on the non-involved hand. According to Helene, it was the most complicated task or heaviest object that was referred to the non-involved hand, and Sally said, “One tries to put as much work as possible on the good hand....I can take...10 kilos on my right arm.” Catherine explained that she could take groceries from the shelf and put them into the basket using only the noninvolved hand, even if the basket was hanging on the forearm of the same arm. Furthermore, other parts of the body might be used instead of the affected hand. One participant described how a jar might need to be placed between the knees to be opened and how a shopping basket might need to be pushed on the floor by the foot instead of being carried. The teeth might be used for opening a banana or opening the lid of a plastic box and the teeth could also be used to bite off part of the food held on the fork instead of using the knife to cut it in pieces. Sandra described how she would tilt the upper part of her body to compensate for the lack of supination in her arm when carrying an open bottle in her affected hand.

**Limiting Choice of Task or Task Performance**

We could see that in activities that offer a number of options, the participants sometimes limited their choice to those options where the decreased function of the hand was the least disturbing. Beata explained that, when in a restaurant, she preferred to order food that is easy to cut; she therefore excluded the option of ordering a piece of meat. Sandra omitted putting away the change when she was at McDonald’s. Instead, she left it on the tray until she was seated even though she thought this gave rise to a risk of someone taking it. In the same way, some of the participants would omit buying a Coke when having a hot dog since they could not handle both objects at the same time. It was sometimes necessary to omit the activity completely. Jenny explained that when she was holding an object in her noninvolved hand and someone wanted to give her a second object, she found it difficult to receive the second object. She therefore tried to avoid these situations: “I think I normally choose to avoid getting into such a situation, I’d just say I couldn’t do it.” Lisa also had an experience of avoiding an activity: “When I was in first class at school and we were doing a play, I did not dare go in there [on stage] because I didn’t want them to find out about my right hand, so I stayed outside, and someone else had to play my part instead.” Sandra said, “…if I can’t do it [cut the food] within a certain amount of time then I get angry, then I give up, then I don’t do it.”

Yet another kind of limitation was seen when activities could not be carried out according to the rules. Beata used only one hand when serving in volleyball; they both commented that the activities should be done by two hands according to the rules. Sometimes there was an experience of breaking implied rules. In the canteen, Sandra ate her potato unpeeled or she peeled it roughly even though this resulted in half of the potato being wasted. She felt this to be inappropriate behavior, but shortage of time led her to choose this strategy, and she said, “The others eat so quickly.” Sandra was also dissatisfied with the amount of water she consumed when using the handheld shower for rinsing her hair since she could not do it in an efficient way. To Beata it was necessary to use the “wrong” hand when shaking hands and she was very bothered about this since she found it impolite to shake hands with the left hand. It was apparent from the descriptions of the participants that these limitations conflicted with the view the person had of her or himself and that he or she wanted to give to others. In order to explain their behavior, the participants at times described themselves as uninterested or lazy.

**The Need for a Repertoire of Strategies**

So far, this study has shown that the choice of strategy can be a difficult dilemma where the strategy with the least negative consequences is sought. To have a range of strategies from which to choose was therefore favorable. However, the ability to find strategies varied both with age and from person to person. Helene stated that over the years she has learned to use both more demanding and more effective strategies. Sally, on the other hand, found it difficult to find alternative ways to perform activities and described how her aunt had helped her with finding out that pulling the chair out with two hands was more efficient than when only one was used.
There was also another benefit of having access to a number of different strategies. Helene explained that if the demands of the activity were raised, she might revert to using an easier strategy for performing the activity. For example, she normally puts on the toothpaste holding the tube in one hand and the toothbrush in the other. If simultaneously talking to someone, she might go back to a strategy she used earlier, when she was a child, putting down the toothbrush on a table and using only the noninvolved hand to squeeze the tube. Thus the level of difficulty of the situation could be met by adjusting the strategy. Helene described the need to constantly learn new strategies—according to the situation and along with her personal development—as a result of being barely able to manage daily activities. “I think that when you live in a kind of ‘border country’ in the way we do, where we can do many things, but not everything, then you are forced to learn new things while growing up.”

Discussion

This study has revealed the process of planning and performing occupations used by young people with hemiplegic cerebral palsy. In this process, the participants used various strategies for managing activities difficult due to their disability. The two main themes showed that, when choosing a strategy, participants had to consider several factors and most often the strategies yielded negative consequences that they felt compelled to accept. Identifying a suitable strategy for carrying out daily occupations therefore appeared to be a matter of weighing the options in specific situations. This concept of identifying a strategy as being a constantly ongoing process corresponds to the concept of a “soft assembly” described by Kielhofner (1995) as a dynamic meeting between the person, the activity, and the environment. According to Kielhofner, it is from this dynamic meeting that behavior emerges. A similar concept is described in a study on the use of strategies by persons with poliomyelitis syndrome, where the choice of strategies is aimed at finding a balance between goals, capabilities, and environmental demands (Thorén-Jönsson, Möller, & Grimby, 1999). In the current study, the desire to find a balance in this dynamic process was apparent when the participants described how they would act differently in different settings, considering factors both external and internal to themselves.

Occupational therapy literature often acknowledges the gap between the ability of the person and the demands of the task. This gap has been described by Holm et al. (1998) as a performance discrepancy. What we found, though, was that even if this performance discrepancy is bridged in one way, by some kind of alternative strategy for performing the activity, another discrepancy may remain, namely a discrepancy between the way the person wishes to perform the activity and what performance is achievable. Even if the participants found that they had made the best choice in a specific situation, it was not always ideal from their point of view since it yielded negative consequences.

Another way of describing the discrepancy between wished and achieved performance would be as a lack of compensation. To compensate means to be equivalent in value to something (Webster’s New Twentieth Century Dictionary, 1983). A compensation in this case would thus be accomplished when the achieved performance and the wished performance are equal in value to the person. In this study, although the participants were able to achieve compensation to some extent, they did not reach full compensation, since to them, the achieved performance was not equivalent in value to the wished performance. By naming these strategies with the more neutral words “alternative strategies,” the discrepancy between wished and achieved performance could be understood as a remaining imbalance. Due to the reasoning above, we chose to use the word “alternative strategies” throughout this study.

In this study, a strong desire to perform competently was apparent. This desire can be understood from the point of view that activity is not merely doing, it is also an opportunity to express the self, and to create an identity (Christiansen, 1999). The impression we think we give others determines our self-appraisal to a high degree, so to appear to be competent is of great importance (Christiansen; Goffman, 1963). The participants described their successes and failures in relation to the occupational performance of nondisabled persons, so living under the same conditions as nondisabled persons in spite of having a minor handicap seems to influence how they value their own performance. This situation seems to increase their wish to conceal the disability. This can be related to what Goffman names “passing”; if possible, people with a minor handicap try to pass as having no handicap. The concealing of the disability may even be subconscious (Goffman). In the current study, concealing the disability was given as one of the reasons why an activity would be omitted. Yude and Goodman (1998) have described this phenomenon in children with hemiplegic cerebral palsy. They state that when the person restricts her- or himself, it is difficult to know whether the person is standing aside because of her or his own free will or because of perceived expectations of others. Such information is important for occupational therapy knowledge and the phenomenon of omitting an activity to solve the problem has been described in occupational therapy literature (Christiansen; Kielhofner, 2002).
The wish not to be different may also explain why the use of technical aids was rarely described by the participants in this study, although an additional explanation for not using technical aids may be the inconvenience of transporting equipment (Culler, 1998) and the need for preplanning revealed in the current study. Another important observation in this study was that the participants attributed themselves with negative characteristics. They described themselves as being lazy or uninterested when explaining their behavior. Goffman (1963) explained that one strategy of “passing” is to claim a property less stigmatizing than the original one to explain their own behavior.

This study has described how young persons with hemiplegic cerebral palsy reason when finding solutions for practical problems. This reasoning can be seen as striving for adaptation. All humans strive to find a way to adapt to their life situation. The aim of adaptation is to maintain a useful relationship to the environment by adapting one’s behavior to the environment as well as adapting oneself to forthcoming events (Nelson, 1988; Thorén-Jönsson, 2000). Adaptation to life is a challenge for any human being, however, the presence of impairments and disabilities may add extra challenges (Thorén-Jönsson). It may be tempting to believe that a minor handicap would lead to a minor difficulty, but the reasoning of the participants in this study has shown that this may be a misleading presumption. It was apparent that participants often experienced shortcomings in various activities, so that selecting a suitable strategy is therefore a constantly occurring event. Whereas an alternative strategy for performing an activity may be used by anyone in order to manage a difficult situation, to the persons in the study it is part of their everyday life. According to Kielhofner (1995), the process of adjusting to or overcoming the challenges of disability may be strongly influenced by the ability to make one’s own choices. It can thus be speculated that having access to a range of strategies and being able to choose how to perform in various situations might be a prerequisite for a successful adaptation.

Implications for Occupational Therapy

This study has suggested that an alternative strategy may be useful and preferable in one situation but not in another. Having a broad range of alternative strategies from which to choose allows the person to adjust the strategy to the situation. For the occupational therapist it may therefore be important to support the person in achieving competence in finding several strategies matching the complexity of the everyday situations (Fisher, 1998). This study has further implied that in order to conceal the disability, it is common also to strive to conceal problems yielded by the disability. The problems encountered by young people with hemiplegic cerebral palsy may therefore easily be overlooked.

One challenge for the occupational therapist may be to differentiate between activity performance that the person is satisfied with and activity performance that is regarded as a problem by the person. One example of concealing problems, mentioned by the participants, is when an activity is excluded. McCuaig and Frank (1991) have stated that it might be important to distinguish between situations where excluding the activity is an alternative performance strategy used to conceal the dysfunction from situations where the activity is excluded due to lack of interest. Finally, the participants in the study have shown that being fully integrated in society and having hemiplegic cerebral palsy often yield an experience of being exposed to the valuation of oneself by others. It may therefore be of value to offer treatment to these persons in groups, creating meeting places where they can share both experiences and practical advice with each other.

Limitations and Directions for Future Research

One limitation in this study may be that the participants in the first group (individual interviews) were selected according to the criteria for a quantitative study. If the selection of participants had been governed by the aims of the current study, people specifically picked out as able and willing to express themselves extensively and thus generate much data in the interviews could have been recruited. In the selection of participants for the second data collection (the focus group), this aspect was acknowledged. Gender was not a criterion, however, by chance, there were many females in a row on the list that was followed for choosing candidates in the first data collection. This happenstance resulted in only two males taking part in the study.

Since many everyday activities are typically automatic and subconsciously organized, one might question whether or not activity-related processes can be explicitly described by interviewees. In the current study, the problem of verbalizing such knowledge was met by keeping the discussion on a practical rather than a theoretical level. Furthermore, the participants in the individual interviews had the opportunity to physically handle practical objects. In the focus group, discussion on a practical level also contributed to achieving rich information while the participants explained their performance to each other on a detailed level, comparing it and seeing differences and similarities.

Finally, understanding how persons with disabilities go about solving their occupational problems is an important
concern for occupational therapy (McCuaig & Frank, 1991). The circumstances of the situation along with the consequences related to different strategies are important considerations for clients’ decision-making processes. In addition, findings from this study suggest a difference between individuals related to how they find and use alternative strategies. Further exploration of the ability to use various strategies might be useful for occupational therapists in their work with enabling individuals with hemiplegic cerebral palsy to carry out their daily occupations successfully.

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References


