Eighty percent consensus was reached for statements three, six and eight. The second round questionnaire items included in the Delphi survey are represented in Table 1. After the second round of the Delphi survey, 80% consensus was reached on all the statements and options. These results reflected a reliable consensus of opinion of the participants.

Discussion
Results showed that a CSC has teaching and learning possibilities in the training of Occupational Therapy students. These possibilities include the following: certain teaching and learning aims are possible; it will add value to the learning experience of OT students in South Africa; and it will create learning opportunities and environments ensuring the quality of teaching and learning of certain aspects of the curriculum. These results concur with the experience of the OT departments in the Netherlands4 and the reasons for developing clinical skills centres in Great Britain.5 It is important to acknowledge that the learning environment in the CSC has to be applicable to the South African population. Additional planning and resources will also be necessary to establish and fully utilise a CSC.

A limitation of the study could be that the participants in the Delphi survey, although experienced academics, were experts in certain fields of OT, which could have influenced their opinion.

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The value of beadwork for women living with HIV/AIDS

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Prejudice and stigma against people living with HIV/AIDS in South Africa often mean that people infected with HIV are excluded from formal employment. Women, who experience the highest prevalence of HIV/AIDS in sub-Saharan Africa1 and the highest incidence rate in South Africa2, also in many cases, have to look after families as single parents. As a result of this, women living with HIV/AIDS often become part of the informal sector; earning income through crafts such as beadwork.

This qualitative study explored the way in which women living with HIV/AIDS experience beading as an income generating occupation within the Positive Beadwork Project (PBP), an initiative of the Kidzpositive Family Fund. Five women were interviewed using both in-depth individual interviews and focus groups. Seven themes emerged from the data: Guaranteed income; Skill development; Beadwork sparks creativity; Sharing and support; Fulfilment of roles; Beadwork is challenging and Lack of community support.

Key words: Beadwork, HIV/AIDS, occupation, and income generation

Introduction
Beadwork is used as an income generating occupation by many Non-Profit Organisations (NPO’s) in South Africa, particularly organisations working with people living with HIV/AIDS. The Kidzpositive Family Fund established the Positive Beadwork Project (PBP), to enable women who are infected by the Human Immunodeficiency Virus (HIV) and who are also caregivers to HIV infected children, to earn a steady income.

The Kidzpositive Family Fund is a non-profit organisation registered with the Department of Social Welfare under section 21 of the Non-Profit Organisations (NPO’s) in South Africa, particularly organisations working with people living with HIV/AIDS. The Kidzpositive Family Fund established the Positive Beadwork Project (PBP), to enable women who are infected by the Human Immunodeficiency Virus (HIV) and who are also caregivers to HIV infected children, to earn a steady income.

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of the Companies Act of 1973. The Fund was initiated in 1998. Its main goal is to raise funds to support health and welfare structures that help combat the impact of HIV-infection. The Fund works towards the comprehensive care of HIV infected and affected infants, children, adolescents and pregnant women, including assisting extended families in their care of affected children. A key component of the Fund is to support the paediatric health care service (both in-patient and out-patient) offered to HIV infected children at Ward G25, Groote Schuur Hospital (GSH). The healthcare service is comprehensive, with a multi-disciplinary team, which includes an occupational therapist, and regular support groups for caregivers.

Mothers whose children attend the paediatric healthcare service (Clinic) at Ward G25, GSH are invited to participate in the PBP. The project model is one where beadwork items are made mostly on a commission basis. Orders of varying volume come in from local and international agencies. As soon as an order is received, a prototype of the product is made, which is then copied by the women involved in the PBP. In order to ensure quality control, the women are required to make a few items onsite in the ward, after which they can take material home to continue their work. Beaders are paid immediately on delivery. Donor funding enables the Kidzpositive Family Fund to pay the women on presentation of completed items. This funding is also used to purchase beading material and reimburse the participants for transport costs incurred as they visit the clinic.

Even with guaranteed financial income, not all women who bring their children to the GSH clinic participate in the PBP. Since its inception in 2002, approximately 130 out of a total of over 500 women who have brought their children to the clinic have participated continuously in the project. With reasons for or against participation in the PBP unknown, the management team of the Kidzpositive Family Fund requested that a research study be conducted with the women involved in the project. The study undertook to explore the experiences of women involved in order to better understand the benefits that they gain from the project, as well as factors that may hinder or prevent involvement. It was anticipated that this would inform management in terms of strategic direction for the project.

Literature review

Southern Africa accounts for 35% of the world’s HIV infected population and approximately one third of all new HIV infections and AIDS deaths. South Africa in particular, has been found to have the highest number of people living with HIV/AIDS. HIV prevalence across the provinces bears substantial differences. While KwaZulu-Natal has consistently carried the highest HIV prevalence in excess of 35% since 2002, the Western Cape carries an HIV prevalence of approximately 15%. ZuZulu-Dirwayi et al found an association between HIV prevalence, gender, race, and socioeconomic status. Being African, a woman and carrying a low socioeconomic status seems to situate individuals within a high risk profile for contracting HIV. This is because African women, particularly those with inadequate economic means are disadvantaged within a society with social inequalities and power relations which often disfavour them. As women form the majority in society, the human Immunodeficiency Virus and the Acquired Immunodeficiency Syndrome (HIV/AIDS) pandemic in South Africa results in a vicious circle of poverty and disease being experienced by this large section of the population.

HIV/AIDS usually affects the whole household, with several members of the family infected. As husbands die from HIV/AIDS, the burden of caring for the household is shifted onto the women. Women whose husbands or partners died of AIDS related diseases also experience social stigma. It is this stigma surrounding HIV/AIDS, which seems to severely limit infected women’s ability to engage in productive work. In instances where individuals lose jobs due to ill-health or HIV stigma, these result in dire psychological effects, which in turn impact negatively on personal well-being and social functioning within families.

Research has shown that adult mortality and morbidity due to AIDS result in a substantial drop in household income. Children and economically inactive adults living with HIV/AIDS within homes compound the women’s burdens. These women will often take up any opportunity to contribute to family income, including limited work offered by NPO’s. Maintaining a worker role in the face of life threatening illness such as AIDS and cancer has been found to contribute to a sense of well-being, and the preservation of physical and mental functioning. Furthermore, Lyons et al found that occupational engagement while faced with serious illness provided individuals with unexpected learning opportunities, and served to divert attention from worry. Many NPO’s involved in HIV/AIDS work offer beadwork or other crafts as a means of generating income, thereby hoping to support infected individuals and their families. However, there are no studies that have explored the experience of those who participate in these projects.

Methodology

This study followed a phenomenological tradition of inquiry as the research design. Within this approach, the researchers sought to understand the experience of beading within the PBP from the participants’ own point of view, and strove for findings to reflect the women’s voices.

Five women were selected using purposive sampling, based on their length of experience within the PBP. Participants were either single or married women and lived in informal settlements in the Western Cape. They were all African. Four out of five of them had beadwork as their only source of income. The researchers conducted one individual in-depth interview with each participant, and a focus group involving all participants. A peer counsellor served as interpreter. None of the three researchers could speak isiXhosa fluently although two could understand the language. Interviews were recorded on audio tapes, and then transcribed. The tapes were then destroyed in order to maintain confidentiality. The data gathered was coded and codes were used to develop subcategories. Sub-categories were collapsed into categories, which were used to inform the key themes that emerged.

To ensure rigour Guba and Lincoln propose four criteria for evaluating qualitative research findings and enhancing trustworthiness, namely: credibility, confirmability, transferability, and dependability. To ensure credibility, member-checking was conducted once during analysis as well as at the end when themes were generated. Confirmability was ensured as the researchers searched for disconfirming evidence to the results when doing the second part of member checking. The broad social context for the participants, as well as background information on Kidzpositive is provided in this report in order to give readers some basis for transferability. To ensure dependability, records of raw data were kept, which include transcribed interviews and provide a clear outline of the method of data analyses. These records were reviewed by the research supervisor and were available for scrutiny by independent reviewers.

Ethical considerations

Prior to the implementation of the study, the proposal was submitted to and approved by the Ethics Review Committee of the School of Health and Rehabilitation Sciences at the University of Cape Town. Ethical principles as outlined by Hopkins and Smith were adhered to in the study, as indicated by the following:

- All participants signed informed consent forms prior to the commencement of the study.
- Confidentiality was ensured by destroying the tapes used to record the interviews; not using names or addresses; and not taking photos of participants. The choice of interpreter who is known to participants was informed by the need to safeguard confidentiality.
- To ensure beneficence, participants were made aware that they would not receive any payment and that they would not suffer any consequences should they decide to discontinue.
Fulfilment of roles

Within their respective lives, participants assumed several roles namely that of wage-earner, mother, wife and friend. The PBP appears to play a significant part in helping these women fulfill their roles. There was appreciation for having assumed a worker role through the PBP, as one participant expressed, “I needed a job, anything”.

Discussion

• Guaranteed income: critical starting point to role fulfillment

A close look at the seven themes that emerged from this study reveals participants’ experience of beadwork within the PBP as centred on their ability to fulfill important life roles. Figure 1 is a visual representation of the interaction between the seven themes, and the catalytic nature of guaranteed income within the PBP.

Guaranteed payment offered by the Kidzpositive Family Fund plays a critical role in the continuous participation of women in the PBP. Even when doing beadwork proves challenging at times, the fact that payment is guaranteed helps the women persevere. Tackling complicated patterns enhances creativity and seems to enable “flow” as described by Csikszentmihalyi. Overcoming challenges is affirming and as these women are increasingly empowered,
they are also enabled to continue fulfilling their roles. The ability of individuals to fulfill important roles is significant for occupational therapists as loss of internalised roles has been associated with decreased life satisfaction\(^{5,16}\).

While guaranteed payment is central to the manner in which doing beadwork may be empowering for women within the PB\(P\), the structural elements through which the project provides a supportive environment should not be overlooked. The training that is offered before-hand so that these women can produce items that can be paid for, available beading material, and the fact that the women get reimbursed for transport costs to attend the clinic are all important. Providing space at the clinic where women can gather and talk about matters that are important to them also plays a crucial role.

As the collection of orders, learning a pattern or dropping completed products and receiving payment are all coupled with visits to the GSH clinic, the women's attendance at support groups becomes regular. Ensuring consistent attendance at support groups is a challenge for organisations working with people living with HIV/AIDS\(^{5,18}\). Regular attendance and continuous sharing helps with forging a collective identity within the PB\(P\), enabling the 'group spirit'. As women encourage each other to pursue healthier lifestyles, they also ultimately influence how they continue to fulfill life roles. Lack of stable income for HIV positive women living in adverse conditions such as those experienced by participants in this current study, often leads to these women engaging in survival tactics such as commercial sex work and selling illicit liquor, thereby exacerbating their susceptibility to re-infections\(^{19,20}\), morbidity, and inability to fulfil important roles.

Participants however, also mentioned a number of issues that are of concern. They pointed to the fact that training offered before beads can take projects home was not sufficient, leading to items at times getting rejected. Back-ache and sleep deprivation as a result of worrying about meeting deadlines signify potential health risks for a population that is already immune compromised.

- **Adverse context determines needs**

The themes, as well as the interaction between them however, cannot be viewed separately from the context within which participants live as HIV positive women. The introduction highlighted the burden that HIV infected women carry within society, as often they are also mothers with family members who are infected as well. stigma surrounding HIV/AIDS, and gender inequalities within the South African context, compounds this burden. An additional factor contributing to the plight of these women is the high level of unemployment within South Africa, particularly in informal settlements\(^{21}\) where the majority of the women live in the Western Cape. High unemployment rates and stigma against HIV/AIDS within communities may explain the lack of support participants experienced from some community members. The fact that these women may be thriving despite their HIV status may bring out feelings such as envy or challenge negative perceptions about HIV/AIDS. Prejudice however was experienced from strangers. Neighbours and family members showed interest and were supportive of the women.

Living within a context that may be unsupportive of women living with HIV/AIDS and lacking in employment opportunities made these women open to participating in the PB\(P\). The relationship between the women's personal circumstances and their willingness to participate in the PB\(P\) is important. This relationship probably explains why not all women who bring their children to the GSH clinic take up the opportunity to participate in the project. Women who may have better prospects of employment, or are socio-economically well positioned may not have a need to do beadwork. The possible association between beadwork and HIV/AIDS and the apparent accompanying prejudice within communities should however not be overlooked.

<table>
<thead>
<tr>
<th>Needs according to existential characteristics</th>
<th>BEING (personal or collective attributes)</th>
<th>HAVING (institutions, norms, tools)</th>
<th>DOING (personal or collective actions)</th>
<th>INTERACTING (spaces or atmospheres)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs according to axiological characteristics</td>
<td>1/ Physical health, mental health equilibrium, sense of humour, adaptability</td>
<td>2/ Food, shelter, work</td>
<td>3/ Feed, procreate, rest, work</td>
<td>4/ Living environment, social setting</td>
</tr>
<tr>
<td>Protection</td>
<td>5/ Care, adaptability, autonomy equilibrium, solidarity</td>
<td>6/ Insurance systems, savings, social security, health systems, rights, family, work</td>
<td>7/ Co-operate, prevent, plan, take care of, cure, help</td>
<td>8/ Living space, social environment, dwelling</td>
</tr>
<tr>
<td>Affection</td>
<td>9/ Self-esteem, solidarity, respect, tolerance, generosity, receptiveness, passion, determination, sensuality, sense of humour</td>
<td>10/ Friendships, partners, family, partnerships, relationships with nature</td>
<td>11/ Make love, caress, express emotions, share, take care of, cultivate, appreciate</td>
<td>12/ Privacy, intimacy, home, spaces of togetherness</td>
</tr>
<tr>
<td>Understanding</td>
<td>13/ Critical conscience, receptiveness, curiosity, astonishment, discipline, intuition, rationality</td>
<td>14/ Literature, teachers, method, educational and communication policies</td>
<td>15/ Investigate, study, educate, experiment, analyse, meditate, interpret</td>
<td>16/ Settings of formative interaction, schools, universities, academic groups, communities, family</td>
</tr>
<tr>
<td>Participation</td>
<td>17/ Adaptability, receptiveness, solidarity, willingness, determination, dedication, respect, passion, sense of humour</td>
<td>18/ Rights, responsibilities, duties, privileges, work</td>
<td>19/ Become affiliated, cooperate, propose, share, dissent, obey, interact, agree on, express opinions</td>
<td>20/ Settings of participative interaction, parties, associations, churches, communities, neighbourhoods, family</td>
</tr>
<tr>
<td>Idleness</td>
<td>21/ Curiosity, receptiveness, imagination, recklessness, sense of humour, lack of worry, tranquility, sensuality</td>
<td>22/ Games, spectacles, clubs, parties, peace of mind</td>
<td>23/ Day-dream, brood, dream recall, old times, give way to fantasies, remember, relax, have fun, play</td>
<td>24/ Privacy, intimacy, spaces of closeness, free time, surroundings, landscapes</td>
</tr>
<tr>
<td>Creation</td>
<td>25/ Passion, determination, intuition, imagination, boldness, rationality, autonomy, inventiveness, curiosity</td>
<td>26/ Abilities, skills, method, work</td>
<td>27/ Work, invent, build, design, compose, interpret</td>
<td>28/ Productive and feedback settings, workshops, cultural groups, audiences, spaces for expressions, temporal freedom</td>
</tr>
<tr>
<td>Identity</td>
<td>29/ Sense of belonging, consistency, differentiation, self-esteem, assertiveness</td>
<td>30/ Symbols, language, religions, habits, customs, reference groups, roles, groups, sexuality, values, norms, historic memory, work</td>
<td>31/ Commit oneself, integrate oneself, confront, decide on, get to know oneself, recognise oneself, actualise oneself, grow</td>
<td>32/ Social rhythms, every day settings, setting which one belongs to, maturation stages</td>
</tr>
<tr>
<td>Freedom</td>
<td>33/ Autonomy, self-esteem, determination, passion, assertiveness, open mindedness, boldness, rebelliousness, tolerance</td>
<td>34/ Equal rights</td>
<td>35/ Dissent, choose, be different from, run risks, develop awareness, commit oneself, disobey, mediate</td>
<td>36/ Temporal/spcial plasticity</td>
</tr>
</tbody>
</table>
The conceptualisation of needs in the H-SD approach as multiple themes in the current study also serves as an expression of who choose to participate in beadwork do so because their challenges in their lives. Max-neef’s Human Scale Development (H-SD)\textsuperscript{22,23,24,25} approach provides a useful theoretical framework against which the impact of the PBP in the lives of these women can be viewed. The H-SD matrix (Table 1 on page 8)\textsuperscript{25} outlines nine axiological categories (referring to things human beings value) of ‘subsistence’, ‘protection’, ‘affection’, ‘understanding’, ‘participation’, ‘idleness’, ‘creation’, ‘identity’ and ‘freedom’, which are cross-referenced with four existential categories (concerned with the meaning and purpose that relationships have for a person) of ‘being’, ‘having’, ‘doing’ and ‘interacting’. Subsistence, affection, participation, creation, identity, doing and interacting are needs identified in the matrix which beading within PBP helps to satisfy.

A defining feature of the H-SD approach that differentiates it from other needs theories such as Maslow’s hierarchy of needs is a clear distinction between human needs (that are fundamental to all humans across cultures and contexts) to live meaningful and fulfilling lives, and satisfiers (the particular means by which different societies or communities are able or unable to realise these needs)\textsuperscript{25}. Human needs are seen as finite, few and classifiable. Satisfiers, on the other hand, are subject to change, and are determined by historical factors and specific social and cultural circumstances. While fundamental needs are universal, they are felt at varying degrees depending on the diversity of “personal/collective attributes and contexts”\textsuperscript{25,2023}. Women who choose to participate in beadwork do so because their life circumstances determine that their participation is the best available means to meeting fundamental needs. The interaction of themes in the current study also serves as an expression of the conceptualisation of needs in the H-SD approach as multiple and interdependent.

Conclusion

It is evident that, to the women who participated in this study, beadwork is not only an act of threading beads on a piece of thread as an outsider may perceive it to be. For these women, beadwork means: being able to generate income that provides for their families’ needs, fulfilling meaningful roles, and having a safe place where they can openly discuss their problems, hence gaining a sense of belonging. The opportunity to learn new skills seems to have improved these women’s outlook on life as it enabled them to begin setting goals for the future.

It is also evident that the meaning derived from engaging in any occupation is subjective and it is strongly shaped by the individual’s socio-economic and socio-cultural context, as well as available opportunities. Beadwork for the women participating within the PBP holds a much deeper meaning than the researchers could have imagined.

There seems to be two possible explanations as to why some women who bring their children to the GSH clinic do not participate in PBP While their personal circumstances may be such that they do not need the income or support offered by the project, it may also be that the association between beading and HIV/AIDS within communities serves as a deterrent.

Recommendations

Guaranteed income for beaders plays a critical role in the PBP’s ability to help meet diverse needs for the women living with HIV/AIDS. The PBP is able to guarantee payment due to its positioning within the KidzPositive Family Fund which is able to attract funding from major donors, as well as the project’s business model through which beadwork is produced mainly on commission. Skills in grant writing to attract donor funding, as well as the ability to identify niche markets for potential products are key for any health-care practitioner, including occupational therapists who wish to work within NPO’s. These skills need to be incorporated in under-graduate or post-graduate education for occupational therapists.

From the concerns raised in relation to challenges in beadwork it seems this needs to be addressed. Given the specific issues pertaining to back-ache and sleep deprivation, life skills should be incorporated within the training of women within the PBP as well as support groups. The beaders could be taught time and stress management techniques, so as to enable them to handle demands in all aspects of their lives. Through workshops, posters with pictures and brochures, beaders could be educated about their work spaces (furniture) and good posture when engaging in beadwork so as to minimise the risk of work-related back pain.

A study that is focussed directly on women who bring their children to the GSH Paediatric healthcare service but do not participate in the PBP should be undertaken in order to explore reasons for their non-participation more directly.

References

16. Larsson M and Brännholm I-B. Approach to Goal-planning in Occupational Therapy and Rehabilitation. Scandinavian Journal of Occupational Therapy — Volume 40, Number 2, August 2010
ABSTRACT

An Assessment of Occupational Therapists’ and Physiotherapists’ knowledge and perceptions concerning the treatment of patients with HIV and AIDS

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With the prevalence of the Human Immuno-deficiency Virus (HIV) being approx 18% in South Africa, it is highly likely that occupational therapists (OTs) and physiotherapists (PTs) working in hospitals will be in daily contact with patients who are HIV positive. It is therefore important that these therapists be knowledgeable about the condition, its causes, progress and the rehabilitative intervention if they are to make a difference in the lives of these patients. This study therefore aimed at evaluating the knowledge and perceptions that a sample of OTs and PTs had of HIV and AIDS as previous studies had found the knowledge and attitudes of health professionals towards these patients to be poor. It was therefore thought to be important to ascertain whether this had changed in more recent years.

A purposive sample of 49 OTs and PTs, drawn from the list of therapists who were employed in the public hospitals of Limpopo Province where both OTs and PTs worked, were selected for the study. These therapists were required to answer a questionnaire which contained both open and closed questions covering knowledge and perceptions of HIV and the Acquired Immune-Deficiency Syndrome (AIDS). The questionnaire was given to the therapists at specially organised meetings at each of the hospitals selected. Thirty five therapists who attended these sessions, answered the questionnaire.

The findings of this study confirmed that of other researchers, namely that there is a relatively poor knowledge base of HIV and AIDS, and therapists generally are uncomfortable being in contact with this type of patient. Thus indicating that, in spite of the increased number of patients who are HIV+ and who have AIDS and the consequent increase in contact between therapist and client, the knowledge base of OTs and PTs in this sample was no different from that found in previous studies. Thus pointing out that there is an urgent need to address these deficiencies through training and mentoring.

Key words: HIV, AIDS, transmission modes, stages of HIV progression, therapy.

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