

The value of beadwork for women living with HIV/AIDS

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ABSTRACT

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 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 deaths³. South Africa in particular, has been found to have the highest number of people living with HIV/AIDS⁴. 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%⁵.

Zungu-Dirwayi *et al*⁴ 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 them⁴. As women form the majority in society⁶, the Human Immuno-deficiency Virus and the Acquired Immune-Deficiency 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 families⁷.

Research has shown that adult mortality and morbidity due to AIDS result in a substantial drop in household income⁸. 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 functioning⁹. Furthermore, Lyons *et al*¹⁰ 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 families¹¹. 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 voices¹².

Five women were selected using purposive sampling, based on their length of experience within the PBP¹². 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 sub-categories. Sub-categories were collapsed into categories, which were used to inform the key themes that emerged.

To ensure rigour Guba and Lincoln¹³ propose four criteria for evaluating qualitative research findings and enhancing trustworthiness, namely: credibility, confirmability, transferability, and dependability. To ensure credibility or believability of the findings, 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 Smith¹⁴ 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.



- ❖ To ensure non-maleficence, participants were never forced to discuss issues that they felt uncomfortable to discuss.

Limitations

During individual in-depth interviews, two participants expressed fear that by getting involved in the study they may jeopardise potential personal benefits from the project in the future, even though the researchers had assured them of confidentiality. It is possible that participants may have been cautious about what they chose to share and steered away from negative comments about the project, particularly in the focus group.

Findings

From inductive analysis, the researchers identified the following seven themes:

• Guaranteed income

On a weekly basis, women brought in their completed orders and received their earnings. *"We are at least guaranteed a payment of R150 per week which one gets if she completed her orders."* Participants felt this was helpful and felt privileged because they were guaranteed money every week. They had a fixed, stable budget to rely on.

• Skill development

All participants were unemployed before they started with the PBP. Two of them had never been employed. Through the project, women were equipped with beading skills as well as the ability to use the bank. They believe that the acquired skills put them in a position to empower themselves. The empowering nature of being a beader within the PBP is encapsulated in the quote from one participant, *"Now I am able to plan for the future."*

• Beadwork sparks creativity

Participants felt there was a great deal of room for creativity in beading. Orders were different all the time. They worked from a pattern and the process of trial and error increased their creativity. Pride was often experienced on completion of complicated projects. *"I am proud of my products."* Participants also spoke about the engaging nature of beadwork, reflected in the comment, *"Beadwork is addictive, I can just keep going, it fights boredom."*

• Sharing and support

Guaranteed income coupled with the support from other women resulted in a positive atmosphere within the PBP. *"When doing beading at home I no longer feel alone because I am always reminded of the positive group spirit at 'Kidzpositive.'" The women experienced a sense of belonging and knew they belonged to a group of helpful people and who were important in each other's lives. The supportive environment motivated them to work harder towards following healthier lifestyles. This was a safe environment where they discussed problems they encountered when doing beadwork and those they experienced in life generally. "I feel free to discuss my problems here because we are in the same boat." As they had similar problems, they advised each other through personal real lived experiences and what they thought worked in different situations. "It is better to talk to people who have been in the same situation, understand how they coped and choose the strategy that best suits you."*

Through their involvement in the beadwork, women joined a new social circle and made friends. *"...Beadwork has also assisted me to meet lot of people ... I did not know many people here because I originally come from Jo-burg."* Working together enabled the women to support each other emotionally.

• 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 fulfil their roles. There was appreciation for having assumed a worker role through the PBP, as one participant expressed, *"I needed a job, anything"*.

Assuming the worker role within the PBP enhanced meaning in other significant roles. As mothers, the participants' chief concern was to provide basic needs for their children. By securing weekly income through beading, these mothers were able to contribute financially to food, clothing, shelter, school costs, as well as transport to school. Families understood why beadwork was important to these women. They knew the amount of time that the beadwork would take whenever they brought work home but valued the financial benefits. Participants indicated that family members were supportive of them. Support included encouraging words, making the working area comfortable as well as helping with the completion of orders. At times husbands and sons would support in a manner not customary within traditional Xhosa homes, as indicated by the following comment:

"They sometimes help with cooking and cleaning, so that I can bead."

• Beadwork is challenging

Participants felt that, like most jobs, beading presented a number of challenges. Strict quality control meant that poorly beaded items were rejected and the beader would lose some income. Although the women found the quality control strict they understood it to be necessary. Complicated patterns and large orders meant that beadwork occupied a significant portion of the women's time. Two participants indicated that beadwork was time consuming, tiring, and caused back pain. One participant reported losing sleep in order to meet deadlines.

• Lack of community support

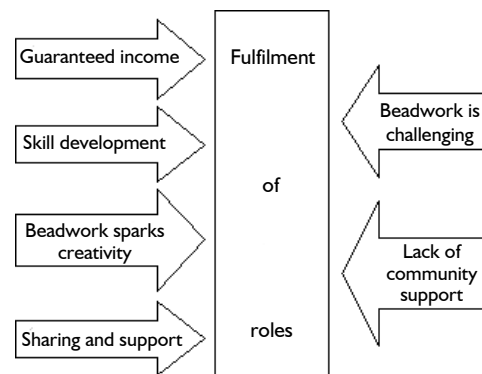
Participants received mixed reactions from the communities within which they lived around their beading. These ranged from curiosity to apparent prejudice. While neighbours would often comment and ask questions regarding items participants were working on, negative reactions were sometimes received from the general public. There appears to be a perception that doing beadwork is associated with HIV/AIDS in communities. A participant overheard a fellow community member saying, *"I will never do beadwork, I am not HIV positive"*.

Discussion

• Guaranteed income: critical starting point to role fulfilment

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 fulfil 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.

Figure 1: Interaction between the seven themes



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 Csikszentmihalyi¹⁵. 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 fulfil important roles is significant for occupational therapists as loss of internalised roles has been associated with decreased life satisfaction^{9,16}.

While guaranteed payment is central to the manner in which doing beadwork may be empowering for women within the PBP, 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^{17, 18}. Regular attendance and continuous sharing helps with forging a collective identity within the PBP, 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 beaders 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 settlements²¹ 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 PBP. The relationship between the women's personal circumstances and their willingness to participate in the PBP 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 1: Human Scale Development Matrix^{23:206-7}

Needs according to existential characteristics	BEING (personal or collective attributes)	HAVING (institutions, norms, tools)	DOING (personal or collective actions)	INTERACTING (spaces or atmospheres)
Needs according to axiological characteristics				
Subsistence	1/ Physical health, mental health equilibrium, sense of humour, adaptability	2/ Food, shelter, work	3/ Feed, procreate, rest, work	4/ Living environment, social setting
Protection	5/ Care, adaptability, autonomy equilibrium, solidarity	6/ Insurance systems, savings, social security, health systems, rights, family, work	7/ Co-operate, prevent, plan, take care of, cure, help	8/ Living space, social environment, dwelling
Affection	9/ Self-esteem, solidarity, respect tolerance, generosity, receptiveness passion, determination, sensuality, sense of humour	10/ Friendships, partners, family, partnerships, relationships with nature	11/ Make love, caress, express emotions, share, take care of, cultivate, appreciate	12/ Privacy, intimacy, home, spaces of togetherness
Understanding	13/ Critical conscience, receptiveness, curiosity, astonishment, discipline, intuition, rationality	14/ Literature, teachers, method, educational and communication policies	15/ Investigate, study, educate, experiment, analyse, meditate, interpret	16/ Settings of formative interaction, schools, universities, academic groups, communities, family
Participation	17/ Adaptability, receptiveness, solidarity, willingness determination, dedication, respect, passion, sense of humour	18/ Rights, responsibilities, duties, privileges, work	19/ Become affiliated, cooperate, propose, share, dissent, obey, interact, agree on, express opinions	20/ Settings of participative interaction, parties, associations, churches, communities, neighbourhoods, family
Idleness	21/ Curiosity, receptiveness, imagination, recklessness, sense of humour, lack of worry, tranquility, sensuality	22/ Games, spectacles, clubs, parties, peace of mind	23/ Day-dream, brood, dream recall, old times, give way to fantasies, remember, relax, have fun, play	24/ Privacy, intimacy, spaces of closeness, free time, surroundings, landscapes
Creation	25/ Passion, determination, intuition imagination, boldness, rationality, autonomy, inventiveness, curiosity	26/ Abilities, skills, method, work	27/ Work, invent, build, design, compose, interpret	28/ Productive and feedback settings, workshops, cultural groups, audiences, spaces for expressions, temporal freedom
Identity	29/ Sense of belonging, consistency, differentiation, self-esteem, assertiveness	30/ Symbols, language, religions, habits, customs, reference groups, roles, groups, sexuality, values, norms, historic memory, work	31/ Commit oneself, integrate oneself, confront, decide on, get to know oneself, recognise oneself, actualize oneself, grow	32/ Social rhythms, every day settings, setting which one belongs to, maturation stages
Freedom	33/ Autonomy, self-esteem, determination, passion, assertiveness, open mindedness, boldness, rebelliousness, tolerance	34/ Equal rights	35/ Dissent, choose, be different from, run risks, develop awareness, commit oneself, disobey, meditate	36/ Temporal/special plasticity



This prejudice may be a strong deterrent for women from participating in the PBP.

• The PBP helps satisfy fundamental human needs

Through guaranteeing income and providing structural support for the women to develop skills, become creative, share with each other, and fulfil meaningful roles, the PBP is able to impact significantly on the lives of women who face immense challenges in their lives. Maslow's Human Scale Development (H-SD)^{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)²³ outlines nine axiological categories (referring to those 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)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"^{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.

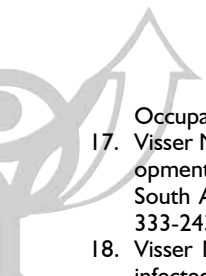
From the concerns raised in relation to challenges in beadwork it seems this area needs to be addressed. Given the specific issues pertaining to back-ache and sleep deprivation, life skills should be incorporated within the training of women within the PBP as well as support groups. The beaders could 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.

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