Holistic Approach to Participant Care

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Teamwork at Zengeza
Introduction

- During study participation, our participants interact with many people
- Male partners, Relatives and Community in general
- Disharmony in the community may arise at any time between participant and any of the people listed above
- May affect participant’s physical, mental and social well being
- May even result in **social harm**
Social Harm

- **Social Harm**—non medical adverse consequence, occurs when a participant experiences difficulties in personal relationships with partner, family members and the community as a result of their participation in the study.
- To date, no reported social harm at Zengeza
- Interesting case of discord between participant and family
- Not related to study participation, hence not a social harm *per se*
- We therefore just called it “Participant Harm”
Participant 318-30063-8, 23 year old orphan, presented to clinic after month 6 visit with:

- **Suicidal ideation** due to persistent domestic violence
- Verbally abused by husband and in-laws
- Physically abused by paternal grandmother
- Sexually and financially abused by husband

- **Homelessness**
  - Evicted by husband and his relatives
  - Evicted by paternal grandmother

- **Disowned by relatives**
  - Paternal grandmother, “*She is a prostitute like her mother*”
  - Paternal uncle, “*Don’t bother me about your marital problems. I will only intervene when I hear that your husband has killed you!*”
Best Practice for Zengeza

- Treat participants as individuals and we accept/address their unique situations.
- Address participant’s social, physical, emotional concerns and do not just end with study-specific procedures only.
Participant Harm Management

- Comprehensive counselling was done.
- Appropriate medical care was provided.
- The following referrals were made:
  - The Police – to deal with assault
  - Musasa Organisation against Gender Based Violence
  - Participant started off a small income generating project
  - The Shelter for Abused women – to provide housing and subsistence for participant and her 3 year old asthmatic daughter.
  - The Shelter for Abused women - Medical intervention for the daughter who did not have her medicines
Participant Harm Management

- The Shelter for Abused women – located at an undisclosed site for the women’s safety
- Our plan was for The Shelter to bring participant to Musasa who would bring participant to site for study visits
- Courtesy calls were made by the study team to follow up the referrals.
- Participant now re-united with family and back in the family home
- We are not only concerned about the needs of our participants, but also of the well being of the community where our studies are conducted
Next Steps

- After this case, site staff realised that community strife probably arising from general ill-health, lack of health information and lack of recreation in Chitungwiza.
- This could adversely affect ASPIRE.
- We decided to improve community health by engaging organisations providing psychosocial services at a larger scale.
- To target the Chitungwiza community.
- We incorporated Social Responsibility Day (SRD) activities into the previously planned Community Awareness Campaign (CAC).
Informative Banner

UZ - UCSF Collaborative Research Programme in Women's Health

COMMUNITY AWARENESS & SOCIAL RESPONSIBILITY DAY
HIV PREVENTION RESEARCH TO PROMOTE WOMEN'S HEALTH & EMPOWERMENT BY INVOLVING MEN AND COMMUNITIES

MTN
microbicide trials network

ASPIRE
A Study to Prevent Infection with a Ring for Extended Use

Madzimai, Tsvakiridzo Ndeyedu!
SRD and CAC

- Education and Recreation – Drama, Disco, Netball and soccer matches
- Overview of ASPIRE, dispelling of myths/misconceptions – by ASPIRE staff and CAB Members
- Free medical consultations and examinations
- Musasa overview of services offered – GBV
- Population Services International – HTC, FP Services
- Earth link – load shedding/rainy season approaching, discussed electrical safety in the home
- Local leaders – “Stop Littering!”
- This event was wholly sponsored by our partners
Man-to-man chat at half-time!
Women’s Break Out Session
Achievements

- Attended by about 300 men and women of all ages
- 52 received free medical consultations/examinations
- 83 clients accessed HTC services.
- 6 couple-clients went through HTC including 2 pregnant.
- 10 clients tested HIV positive and 8 of them had CD4 tests done on site, with appropriate referrals.
- 80 clients received family planning counselling and services.
- Prevalence rate -12%.
- 50 HIV negative women were seen, encouraged to visit ASPIRE clinics to find out more about the study
Conclusion

- Healthy, happy and informed community will positively affect ASPIRE via:
- Timely accrual
- Good adherence
- Remarkable retention
Acknowledgements

- Chitungwiza Community
- CAB
- Staff
- Study participants
- FHI
- NIH
Discussion

How are other ASPIRE Sites Managing similar scenarios?

Are shelters available and functional in your research communities?
Thank you!!