I SURVIVED CANCER: PHENOMENOLOGICAL ANALYSIS OF THE SURVIVORS' LANGUAGE

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ABSTRACT: The study attempted to understand the feelings of people who have survived cancer, through qualitative research with Heidegger’s phenomenological approach. The study subjects were five cancer survivors, followed up during 2004 and 2005 through a university extension project in the northwestern region of the state of Paraná. Phenomenological interviews were held to capture the survivors’ feelings, at their homes, during January and February 2013. “How is it for you to have survived cancer?” was the orienting question. Four ontological issues emerged from the analysis of their discourses: (re-) remembering the vigor of having been; (re-) encountering spirituality; fear of the disease’s recurrence; forgetting the temporality of living with cancer. We conclude that, in their being-healed, patients live with anxiety, that throws them into a distressing state for fear of recurrence, as well as enabling them to find a new meaning to life.

DESCRIPTORS: Neoplasms. Survivorship. Nursing care.

SOBREVIVI AO CÂNCER: ANÁLISE FENOMENOLÓGICA DA LINGUAGEM DOS SOBREVIVENTES

RESUMO: Buscou-se compreender os sentimentos de pessoas que sobreviveram ao câncer, por meio da pesquisa qualitativa, com a abordagem fenomenológica heideggeriana. Foram sujeitos cinco sobreviventes de câncer, acompanhados entre os anos de 2004 e 2005 por um projeto de extensão universitária no Noroeste do Paraná. Para captar os sentimentos dos sobreviventes, foi utilizada a entrevista fenomenológica. As pessoas foram entrevistadas, no próprio domicílio, entre os meses de janeiro a fevereiro de 2013, com a seguinte questão norteadora: “Como está sendo para você ter sobrevivido ao câncer?” Da análise dos discursos, emergiram quatro temáticas ontológicas: (Re) Lembrando o vigor de ter sido; (Re) Encontrando-se com a espiritualidade; Temendo a recidiva da doença; Esquecendo-se da temporalidade de existir com câncer. Concluímos que, em seu sendo-curado, as pacientes convivem com a angústia, que as lança a um estado aflitivo pelo temor da recidiva, como também as possibilita encontrar um novo sentido à vida.

DESCRITORES: Neoplasias. Sobrevida. Cuidados de enfermagem.

SOBREVIVI AL CÁNCER: ANÁLISIS FENOMENOLÓGICA DEL LINGUAJE DE LOS SOBREVIVIENTES

RESUMEN: Buscamos comprender los sentimientos de personas que sobrevivieron al cáncer, por medio de la investigación cualitativa e abordaje fenomenológica heideggeriana. Fueron sujetos cinco sobrevivientes de cáncer, acompañados entre los años de 2004 y 2005 por un proyecto de extensión en el Noroeste de Paráná. Para captar los sentimientos de los sobrevivientes fue usada la entrevista fenomenológica. Las personas fueron entrevistadas, en el propio domicilio, entre los meses de enero a febrero de 2013, con la siguiente cuestión: “¿Cómo es para usted haber sobrevivido al cáncer?” Emergieron cuatro temáticas ontológicas: (Re) Acordándose el vigor de haber sido; (Re) Encontrándome con la espiritualidad; Temiendo la recidiva de la enfermedad; Olvidando de la temporalidad de existir con cáncer. Llegamos a la conclusión que, en su ser-sanado, los pacientes viven con la angustia, que lanza en un estado penoso, por temor a la recurrencia, así como permite encontrar un nuevo sentido a la vida.

DESCRIPTORES: Neoplasias. Sobrevida. Atención de enfermería.
INTRODUCTION

Cancer has been shown to be one of the main causes of mortality in the world, deserving special attention on the part of health professionals so as to mitigate the suffering, as the mortality rate is high, although for many cases, cures occur. When somebody receives a diagnosis of cancer, therefore, which brings the stigma of an incurable illness, there appears in their life the inevitable possibility of death.¹

As a result, being with cancer goes beyond physical pain and emotional discomfort, which cause the person to be immersed in an existential nothingness, due to interfering in the objectives of life of the patient, her family, her work and income. Her mobility, body image and life-style can be drastically changed, temporarily or permanently, producing repercussions which affect all those involved.² Within this temporality, the person moves between the constant shadow of death and the hope of surviving the illness.

Regarding survival following cancer, the literature indicates that, in the United States of America, patient survival has tripled in the last 30 years, indicating nearly 10,000,000 people, due to the advance of discoveries in early diagnosis and of new technologies for treatment. In that country, the patient with a diagnosis of cancer has a 64% chance of survival over five years, compared with a rate of 50% three decades ago.³ In Brazil, according to the National Cancer Institute (Inca),⁴ relative survival expected for all the types of cancer is approximately 50% at five years. However, there is still a need for studies evaluating the survival of patients with cancer, in a more routine and continuous way, over long periods of time, as already takes place in some countries.⁴

The temporality of living with cancer and its treatment pass negative feelings on to the patient, often making her saddened and thinking that things are becoming increasingly difficult. Such thinking supports the feelings of inability and impotence when faced with the situations.⁵

The project “Palliative care for cancer patients and their families” began in 2004, so as to provide a meeting place with patients who experience cancer in their daily life. This has, as a fundamental objective, the accompanying of cancer patients and their families in their homes, the offering of holistic support to these patients and their needs, through the use of the principles of palliative care.⁵

In the above-mentioned project, we noticed that, in experiencing the confirmation of the diagnosis of cancer, the person feels the desire to be cared for, loved, understood, and, principally, to share her concerns and fears.⁷ In this trajectory, we shared the patient’s fear before the uncomfortable possibility of death, which persists in silencing life, which still lived in her body, annihilating not only the private things of the ill person, but also her dreams of living a pleasurable future.

Equally, in having her daily life invaded by a neoplastic illness, the individual has the possibility of finding a new meaning to life and transcending its vicissitudes,⁸ such that the same anxiety which accompanied the patient and her family along difficult paths in search of the cure causes the same to leave the state of collapse in which they find themselves and glimpse the resplendence of a new horizon. Thus, from the rare moments resulting from the temporality experienced by those whose cancer was stabilized, arises the disquiet: what is the meaning of life for the people who survive cancer?

This existential condition causes a different understanding to emerge for care in oncology, transposing a “doing” which goes beyond care for signs and symptoms of the disease, and requires of the health professional a concern with emotional, social and psychological aspects so as to maintain the person’s quality of life. In the light of the above, this study’s purpose was to understand the feelings of people who survived cancer.

METHOD

For this study, we selected qualitative research, with the Heideggerian phenomenological existential approach. Phenomenology places, as the starting point for its reflection, the person who one can know immediately, that is, Man himself, placing him within an ontological dimension. It allows the understanding of the being, as it is that which is hidden in that which is manifested through the language.⁹

Phenomenological verification does not start from a problem but from a questioning. When the researcher questions, she has a trajectory and walks towards the phenomenon, in that which manifests itself, through the language of the person who experiences the situation. Thus, to know something which leads us to the understanding the concepts of the people who survived cancer, we must question them in their mundanity of the world, that is, in their own human world where
they experience the phenomenon to be revealed,9 which constitutes our region of inquiry.

The research subjects in question were from the extension project titled “Palliative care for cancer patients and their families”, elaborated and implanted in 2004 in the Universidade Federal de Maringá, which has monitored patients with cancer receiving palliative care since 2004 to the present day. Between the years 2004 and 2005, the project accompanied 15 people receiving cancer treatment, who continued to be monitored until the situation stabilized, that is, until they no longer presented symptoms of the disease, or until they died. The interest in investigating these peoples’ survival arose in 2012, through the request of a survivor who wished to present her experiences.

In seeking this study’s subjects, in previously-arranged visits, we met eight ex-participants of the project who had survived cancer. Emphasis is placed on the significant number of survivors, considering that the project in question monitored patients with few perspectives of a cure. We reiterated that, in this project, we considered that the palliative care was to be introduced to the cancer patient since their diagnosis, and not only for those with no perspective of a cure.10 As inclusion criteria for the interviewees, besides participation in the above-mentioned project, the patient could not have presented recurrence of the cancer in the last seven years; must live in the city of Maringá in the state of Paraná-PR; and be aged over 18 years old. Those who had other comorbidities prohibiting their participation were excluded, as were those who died before the data collection.

Among the eight patients found, three were excluded, as the disease had recurred in one and she died before the data collection period; a second person moved city, causing us to lose contact; and the third lacked psychological conditions to answer the questions due to the onset of Alzheimer’s disease. As a result, interviews were held in the period of January to February 2013 with the five people who had survived cancer.

As this is a study involving human beings, the ethical aspects regulated by Resolution N. 466/2012 of the National Health Council were observed. The proposal of intention to undertake the study was considered and approved by the Universidade Federal de Maringá’s Standing Committee For Ethics in Research With Human Beings (Opinion N. 233.634). We also make clear that the participants were assured free consent and the liberty to withdraw from the study at any moment if they so wished; confidentiality, regarding the information provided; and anonymity whenever the results were published.

Thus, following the first contact with the former participants in the project, we returned to their homes to explain the research and request their participation. Following the survivor’s authorization, we began the interviews in each person’s home, with the aim of capturing their feelings and also their body language. A digital recorder was used and the recordings produced, based on the subjects’ discourses, will be kept for a period of five years and then discarded.

In our opinion, the description of experiences must involve thoughts, feelings and actions relating to the reality experienced. In this regard we asked the informants the following guiding question: “How is it for you to have survived cancer?” To maintain their anonymity, they were referred to as S1, S2, S3, S4 and S5.

To capture the fullness expressed by the subjects in their languages, we selected the individual analysis of each discourse. Thus, a priori, we undertook close readings of each account, separating the excerpts or units of meaning which, for us, were shown to be fundamental structures of the existence of the participants interviewed.11 A posteriori, we moved on to analyze each account’s units of meaning, undertaking phenomenological selection of the language of each subject,11 which produced ontological themes, analyzed in the light of some Heideggerian ideas, and in the light of the ideas of specialists on the issue and researchers who discuss palliative care.

RESULTS AND DISCUSSION

Based on the analysis of the participants’ language, four ontological themes emerged: (Re-) Remembering the vigor of having been; (Re-) Encountering spirituality; Fear of the disease’s recurrence; and, Forgetting the temporality of existing with cancer.

(Re-) Remembering the vigor of having been

In his work Being and Time, Heidegger presents the interpretation of the authentically existing man, that is, the being-there in her totality. For the thinker, in anticipation of death, being-there exists authentically. The natural ontological foundations of the existentiality of the being-there are the temporality and the historicity.9
In the forward-looking decision, that is, in the originality and authentic form of caring, the man reveals all his potentiality-for-being, it being the case that this potentiality-for-being is manifested in a temporal constitution. It is a primitive temporality which is temporalized in accordance with three ek-stases. What is to come (future), the vigor of having been (past) and the actuality (present).

In this temporality, learning to be an entity for death, the being-there perceives herself to be thrown into the world and experiencing the facticity of her existence. The temporal movement through which she makes the return to her thrownness constitutes the past. In Heideggerian thinking, it is through projecting himself towards the past that the man can sight and take responsibility for his being-in-the-world.

In this temporal projection, the being-there also becomes historical, but the historicity of this being does not reside in the simple fact of the Being-in-the-world being the object or subject of the history, but of having a destiny. In this case, history does not mean only what has passed, but also its origin and meaning for the person. “The human being can return to the past, because life can be summarized, and crystalizes in significant forms, of meaning and value.”

Based on the above, we visualized, in the subjects’ languages, that being cured from cancer in this ik-stante does not erase the memories of their vigor of having been. “The past always has meaning only in the extent to which it is seen from the present.” And, in this actuality, the patients demonstrate anxiety and suffering experienced in the times when they were subjected to the treatment. The time of chemotherapy stands out from the others as having had the most impact, through its effects and characteristics which invade the patients’ lives.

[...]

I survived cancer: phenomenological analysis of the survivors’...
survived cancer allowed the interviewees a new way of seeing the world and the people around them, a fact corroborated by studies which evidenced the reorganization of life strategies and a new signification for the routine facts by patients who experienced cancer in their lives.17-18 In this perspective, spirituality is an important dimension of man, which, added to the biological, intellectual, emotional and social dimensions, constitutes that which differentiates man in his uniqueness and personality.19

Fearing the disease’s recurrence

In the Heideggerian analysis, the disposition or affective tonality is raised regarding the past, when the man eventually retracts to the world of forgetting, to his having-been-thrown. The philosopher states that the disposition is characterized in mood or affectivity, representing the ways that the man expresses himself in the world in his being-thrown. In this temporal analysis of the mood, the author patents the fear and the anxiety.9

The fear is characterized as an inappropriate disposition, as the fear finds its opportunity in the entities which support it, detecting a “malum futurum”. The existential and temporal meaning of the fear constitute a forgetting of oneself. The fear affords the withdrawal of the Being-there from his more appropriate potentiality-for-being and, in this forgetting, he no longer recognizes himself in his surrounding world and does not visualize the various possibilities around him, as, in the fear, the man becomes agitated in relation to the world, becoming afflicted and troubled.9

During the reading of the accounts, we visualize the possibility of the recurrence of the cancer as the intramundane entity which was already present and which can come again to the human beings in this study, provoking in them the feeling of fear in the light of the probability of having once again to experience the presence of cancer in their bodies. This possibility brings into their lives a mixture of fear and uncertainty, which surround the fear of the recurrence and re-approximation with death at every moment in which it is remembered.20
The existential phenomenology of perception analyzes the body not as a physical organism, but sees it as a totality, a structure with relation to the things which are there, that is, the meaning is something which occurs in the body itself. Hence, we also observe, in the account of Survivor 4, that the same reports living in an existential paradox, that is, on the one hand, she once more feels life in her body, but at the same time, lives with the expectation of the reappearance of the disease. This thinking leads us to believe that the experience of being a survivor can only be experienced and felt in all its completeness by the person who survives and who brings hope, as the same is founded upon an important phenomenon in human life, taking on a special relevance in crisis situations.

**Forgetting the temporality of existing with cancer**

The human being in his being-thrown-to-the-world can be manifested inauthentically or authentically. The inauthenticity is a way of Being-there being-in-the-world, but is characterized by abandonment of oneself, that is, the being itself abdicates from itself in favor of the world. In this condition, it forgets its possibility of being a being of care.

In the Heideggerian analysis, the human being is a being-in-the-world with possibilities for transcendence, because “our existence is characterized by a having to be which must, each time, that is, in each new situation, be taken on”. In the light of this, we surmise, in the discourses, that after transcending his existential anxiety before the probability of the recurrence of the disease in his life and, experiencing the temporality of being cured, the Being-there abandons himself to lack of care about himself, overlooking his facticity of being a being thrown away in the world, living at the mercy of the facts and occurrences.

In the accounts, we revealed that the temporality of being a cancer survivor immerses them in a state of existential decadence, losing themselves in the banalities of daily life. And, in this state, they cease to value certain important cares for the continuation of their health.

In particular, I feel like this: I [...] I forget what I had, actually. Last year, I even did something I shouldn’t have, I should have done my check-ups in the beginning of the year, and in the rush I kept leaving it, leaving it and I only went to the doctor in July. There are times when I am like that, so tranquil that I stopped...
survived cancer, we sought not only to glimpse the rest of his life. Thus, the specter of the cancer an individual, leaving marks which last for the confirmation of the cancer and its treatment in this ontological theme, we also surmise that this profession has a relevant role in maintaining the health and quality of life of the people who survived cancer, through planning actions directed towards educational processes and psychosocial support for these beings, raising their awareness regarding the importance of self-care through undertaking tests and being monitored by a doctor as a means of detecting any abnormality at an early stage and, thus, being able to live their lives in a full and healthy way.

We are driven like this, to the reflection on the care practised, so as to provide care which covers the needs of these Beings-in-the-world. In this context, it is essential to look to not only their physical dimension, but to the totality of their being. In our opinion, the need for the professional

REFLECTIONS ON THIS STUDY

In entering the world of the being-there who survived cancer, we sought not only to glimpse the human being, but to understand this being in her temporal existentiality. And, in this experience, this time is the most immediate phenomenal aspect of the temporality. In this situation, he manifests his way of having survived cancer, as, as an ontico-ontological being, the man reveals to his entities around him the happinesses, the sadnesses, and, mainly, the needs which encompass his ontico-ontological priorities.

The existential phenomenological analysis allowed us to understand the interviewees’ feelings, it being the case that, for these, surviving cancer is to find oneself in a temporality which hears, sees and knows; which imagines and expects, and becomes happy and distressed in the context of one’s existential facticity.

Hence, through this study, we understand that, in their being-cured, the people come to live with the fog of the disease in their daily life and, at these times, the anxiety is present and the fear of the cancer’s recurrence throws them into a distressing state, and, in this *ik-stante* of their lives, that people try in every way to forget their vigor of having been, and this attitude causes them not to accept their responsibilities for the present and future.

However, at some points, the anxiety provides new perspective on life, which is reflected in a new way of facing problems and suffering, with only the feeling of gratitude to a superior entity remaining, for everything which remained in the past. In this way, these individuals now live authentically, demonstrating solicitude for their fellow man, and now inauthentically, turning away from their possibilities of remaining cured.

Based in the feelings constructed over time by the survivors, the need is demonstrated to broaden the nursing professionals’ focus, given that this profession has a relevant role in maintaining the health and quality of life of the people who survived cancer, through planning actions directed towards educational processes and psychosocial support for these beings, raising their awareness regarding the importance of self-care through undertaking tests and being monitored by a doctor as a means of detecting any abnormality at an early stage and, thus, being able to live their lives in a full and healthy way.

In his being-in-the-world, the being-there has the liberty of choosing his own path, living life according to his way of being and feeling the world, “which means taking on responsibilities with the present and with the future” 24,27 In the light of this, we can understand from the accounts of S4 and S5 that these demonstrate a way of living fixed to the present. And, imprisoned in this temporality, they let themselves be guided by the situation, overlooking themselves and their care. This attitude may demonstrate that to feel cured is to carry with oneself the ghost of the cancer, as if the same were present in their bodies, but in silence, being able to wake up at any moment. We learn, too, that revealing the phenomenon experienced by the survivors allowed us “the understanding of being in its multiple facets, in its experiences and relationships with the routine world” 26,985

From the analysis of the survivors’ accounts, in this ontological theme, we also surmise that the confirmation of the cancer and its treatment bring with it routine changes which transform an individual, leaving marks which last for the rest of his life.27 Thus, the specter of the cancer and its consternation remain in the memories of those with whom it coexisted, and how it is faced is translated in a form unique to each individual.

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to use time as a listening tool for improving the quality of the care is evident, as the temporality of being a cancer survivor revives feelings of anxiety, originating from not having a person with whom they can share the anxieties which cause them physical or mental discomfort or a means of doing so, thus restricting their quality of life.

In spite of the scale of the feelings which emerged among the survivors, the study has limitations, which do not allow us to generalize its findings to all the cancer survivors; however, the opportunity is repeated to offer health professionals some aspects which encompass the experience of these beings and which deserve due attention in relation to their care.

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"They make money off of us": a phenomenological analysis of consumer perceptions of corruption in Kenya’s HIV response system

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Abstract

Background: Problems with misallocation and redirection of critical resources and benefits intended for PLHIV are not uncommon in Kenya. This study explores corruption in Kenya’s HIV response system and the implications for health outcomes from the perspective of people living with HIV (PLHIV). Although they might not be directly responsible for health care fund management, PLHIV and their advocacy efforts have been central to the development of HIV system response and they have a vested interest in ensuring proper governance.

Methods: This phenomenological study was conducted in 2012 in Kiambu County in Kenya. The study was designed to capture the experiences of a select group of individuals living with HIV and AIDS and subsequent effects on intergenerational wealth transmission. Four focus groups were conducted with self-convened HIV/AIDS peer support groups. Findings related to corruption emerged unexpectedly, albeit consistently, across all four focus groups. To validate core themes within the data, including corruption, two coders independently reviewed and coded the data.

Results: Participants described incidences of resource misallocation, theft, and denial of services across three thematic levels namely at the interpersonal, provider, and institutional levels. Participants described the negative influence of corruption on their health and financial well-being, and propose: (1) strengthening legal protections for assets belonging to PLHIV, (2) direct representation of PLHIV within service agencies, (3) and addressing information asymmetries to inject transparency into the response system.

Conclusion: Our findings add to the growing literature that identifies advocacy among individuals and families impacted by HIV and AIDS to be a useful tool in drawing attention to harmful practices in the HIV response infrastructure; consistent with this movement, communities in Kenya demand greater control over programmatic interventions both at the national and local levels.

Keywords: HIV/AIDS, Corruption, Kenya, Phenomenological study

Abbreviations: AIDS, Acquired immune deficiency disorder; ART, Anti-retroviral therapy; CACC, Constituency AIDS Control Committee; CBO, Community based organization; CCC, Comprehensive Care Centers; CHW, Community health workers; HIV, Human immunodeficiency virus; HTC, HIV testing and counseling; KES, Kenyan shilling; OVC, Orphaned and vulnerable children; PLHIV, People living positive (with HIV); PMTCT, Prevention of mother-to-child transmission; STI, Sexually transmitted infection; USAID, United States Agency for International Development

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Background

Kenya continues to have one of the highest HIV prevalence rates in the world [1]. High prevalence and HIV/AIDS-related deaths prompted the Kenyan government to declare HIV a national disaster in 1999. Although the rate of new HIV/AIDS infections in Kenya has declined steadily since the late 1990s, when the highest rates were recorded [2, 3], 1.6 million Kenyans are reportedly living with HIV [3]. Kenya’s HIV response system is multi-sectorial in nature, characterized by a network of services provided through an array of Ministries and State Departments, County Governments, and various arms of the private and corporate sectors [3]. This broad and overarching response system uses a social justice perspective to integrate prevention and health services, research and development, and organizational development [3]. At the national level, financing and administration of testing and treatment services is the responsibility of the Ministry of Health through The National AIDS and STI Control Program (NASCOP). Other government ministries—such as the Ministry of Labour, Social Security, & Services; Ministry of Education, Science, & Technology—are responsible for administering and delivering auxiliary services such as economic empowerment supports for vulnerable families, education bursaries for children orphaned or made vulnerable by AIDS, and enforcement of anti-discrimination policies.

Although the Kenyan government has developed public agency infrastructure for delivering HIV services, only 18 % of these expenditures are financed through public coffers. Rather, the extensive healthcare needs have meant that the lion’s share of the HIV response costs are borne by international development partners, the corporate sector, and private households [4]. It was estimated that Kenyans spent over US$ 98 million on out of pocket costs in HIV related care in 2011/12 accounting for 13 % of the response system. PLHIV spend approximately seven times more than what the average Kenyan spends on health care [4] which includes medical costs associated with HIV and HIV related illnesses. In 2012, the private and corporate sectors contributed approximately US$ 15.93 million to the HIV response system. They do this providing work place programs such as interventions dealing with stigma and gender relations, pharmaceutical treatment, and inpatient and outpatient care [4]. Finally, international development partners play an integral part in the HIV response system by bearing a significant share of the cost burden—approximately 70 % between 2009/12. This over-reliance on international donor supports raises concerns about the Kenya government’s ability to sustain the response effort.

Corruption in Kenya

Problems with misallocation and redirection of critical resources and benefits intended for PLHIV are not uncommon in Kenya, where corruption is widespread. In a worldwide corruption perceptions index, Kenya was ranked 139 out of 168 nations, with 43 % of those surveyed perceiving corruption as a problem in the health care sector alone [5]. Corruption is defined as public servants’ abuse of their position for personal gain [6]. Kenyans have extensive personal experience with corruption; 77 % of those surveyed about corruption in Kenya reported that someone in their households paid a bribe to the police, 54 % to public registry departments, and 35 % to medical healthcare providers [5]. Within health care and other public systems that support PLHIV, corruption can also manifest as a variety of behaviors among decision makers within public agencies, provider facilities, and community groups. Other examples include kickbacks for procurement decisions, embezzlement, fraudulent claims of services rendered, theft of funding or supplies, charging individuals for services or products that should be free, providing poor quality care, diverting individuals away from public benefits, and excessive absenteeism among providers [7–9]. Bribes and corrupt behaviors may be used both by consumers as a conduit to access legitimate services or by decision makers to gain access to unmerited goods and services.

Regardless of the level at which it occurs, corruption obstructs the delivery of resources, services, medications, and benefits to those who are most in need, unduly impacting low-income Kenyans, and can lead directly to poor health outcomes [10, 11]. Unchecked corruption threatens the stability of international aid, health programming [12], and national economic growth [13]. In addition, corruption can lead to distrust in public institutions and healthcare providers. Especially in healthcare, where patients rely on professionals to consider their best interests, distrust limits individuals’ motivation and likelihood of accessing needed services, and compromises personal health [14, 15].

Conditions that drive corruption

Although corruption among public officials is often driven by individual factors, their behavior is also heavily influenced by organizational, institutional, and cultural contexts [6, 16]. In many cases, corruption is motivated by the potential for personal financial gains, friendship, or family, but made possible by ample opportunity to engage in these behaviors without being held accountable [6]. As large sums of international aid are dispersed throughout complex public systems, weak governance infrastructure, limited integrity policies, poor supervision, and wide ranging personal discretion in decision making allow public officials to misdirect resources without being detected [7, 16]. Another factor may be that decision
Community engagement processes are based on: 1) authentic and policy design, and service delivery. Effective participation and protections through Community Advisory Boards (CAB) but engagement has since expanded to more broad participation in research, advocacy, program and policy design, and service delivery. Effective community engagement processes are based on: 1) authentic

Furthermore, personal, organizational, or cultural values that enable public officials to rationalize their behavior can drive corruption. For instance, weak ethical values, strong social norms, or cultural taboos such as the social stigma associated with HIV/AIDS could legitimate corrupt behaviors [6]. Kenya’s political structure and ethnic heterogeneity has been viewed as a driver of corruption. Kenya has had a long history of political patronage driven by ethnic and regional motivations. The result has been economic inequalities along ethnic, and by extension, geo-political boundaries [18, 19]. These inequalities have bred an environment of ethniccronyism where individuals engage in corrupt activities not purely for private gain but also for the benefit of fellow tribesmen. Indeed, Orjuela [20] cautions that in societies where group identity is paramount, corrupt behaviors and actions in pursuit of “personal again” could extend to include the “collective gain” of a particular group.

Fighting corruption often requires multiple complementary measures that target internal governance, improve transparency, and engage the public in promoting accountability. Internal accountability mechanisms that tighten personnel management, procurement, and oversight processes can reduce the opportunity to misallocate resources. For instance, instituting staff performance appraisals, codes of ethical conduct, mechanisms for reporting and subsequent sanctions for misconduct, and financial incentives for performance could minimize opportunities, pressures, and acceptance of corruption [9].

To complement internal governance initiatives, external mechanisms are needed that engage the public in promoting accountability among systems, providers, and other decision makers. Provider report cards, consumer advocacy or advisory groups, complaint boxes, and health facility charters that advertise the cost of services can promote transparency and information dissemination to the community, empowering patients to challenge corruption [21–23].

Consumer advocacy and the global HIV response
In 1978, the World Health Organization introduced the idea of local involvement and control in the design and implementation of health systems as a necessary mechanism to effectively address public health issues, particularly in the global South [24]. UNAIDS guidelines requiring community engagement were established in 2000. Initially, engagement was focused on research participation and protections through Community Advisory Boards (CAB) but engagement has since expanded to more broad participation in research, advocacy, program and policy design, and service delivery. Effective community engagement processes are based on: 1) authentic participation of a representative group of stakeholders, 2) mutual trust between community and partners, and 3) shared power [25]. Engaged community may lead to greater transparency in the research and implementation processes [26], re-direction of resources to areas of highest need, [27, 28] and locally appropriate services [29]. Consumer advocacy is also associated with increased patient trust in providers. As consumers develop stronger trust in healthcare professionals, they may be more likely to comply with treatment [26, 30]. From a service provision perspective the use of unpaid volunteers in service provision is geared towards increasing the chances of program sustainability. It should be noted that community volunteers account for approximately 40 % of community based organizations’ (CBO) budgets. This is especially salient given that in Kenya funding most likely comes from external donors and is limited (average annual budgets equal approximately US$ 15,000) [31]. However, reliance on under- or uncompensated labor, particularly in communities where needs are great, could be construed as exploitative and is indeed unsustainable in the long run [32]. Thus, even in systems with strong consumer advocacy and involvement, there still remains a strong risk of the misalignment of resources to local needs.

Methods
This study explores consumers’ experiences in Kenya’s HIV response system and describes corruption and implications for personal health and well-being. Consumers [1] describe instances of corrupt behavior at multiple levels of the system, [2] explain the effect of corruptive behaviors on personal health and well-being, and [3] identify potential strategies for improving governance and accountability within the healthcare system.

This phenomenological study was conducted in 2012 in Kiambu, Kenya. Phenomenology allows for the exploration of lived experiences. Unlike grounded theory which focuses on the objective generation or discovery of theory, the phenomenological approach seeks to unearth the deeper meaning of experiences solely from the perspective of an individual’s life experiences [33, 34]. Furthermore, this technique aims to reduce the degree to which conceptualizations of the phenomena are superimposed on research participants’ re-telling and understanding of their experiences. Given the dearth of information on the phenomenon of intergenerational wealth transmission in households at the confluence of poverty and chronic illness, this study was originally designed to capture these experiences among a select group of heads of households. Four focus groups were conducted with self-convened HIV/AIDS peer support groups in the region. In light of the original study’s focus on personal and family asset holdings, the findings
related to corruption presented in this manuscript emerged unexpectedly, although consistently, across all four focus groups.

**Study design, setting, and population**

Kiambu County is home to a mixed economy, with industries and large scale farms on the one hand and small subsistence land holdings and informal housing settlements (slums) on the other. The County Integrated Poverty Plan 2013-17 places the county’s poverty rate at 21.75%. Kiambu county’s HIV prevalence rate stands at 3.8% and ranks 38th among Kenya’s 47 counties [35]. Admittedly, Kiambu County has inadequate health care services with a doctor/patient ratio of 1:17000 and the nurse/patient ratio at 1:1300. In addition the county has one level-five hospital, namely, Thika District Hospital [36]. Although located in a region predominated by the Kikuyu tribe, the county’s proximity to the capital city Nairobi and its peri-urban economy means that it is home to Kenyans from all ethnicities. Kenya has at least 40 different ethnic tribes each with unique intergenerational wealth transmission norms and rules. We documented understanding of this issue from different cultural perspectives by deliberately seeking peer support groups that were as culturally diverse as possible, although homogeneity was not an exclusion criteria.

A community gatekeeper assisted with recruitment by publicizing the study among local support groups. The gatekeeper had access to these groups through her participation with the local Constituency AIDS Control Committee (CACC). CACC’s are local bodies charged with the coordination of HIV and AIDS activities. HIV Peer support groups are required to register with their local CACC [37]. Participating groups were those that were able to convene with at least ten group members present and had to be able to commit at least two hours to the interview.

These recruitment procedures yielded a diverse sample, with regard to age, gender, and tribe. Of the 45 respondents 67% were female. The respondents ranged in age from 28 to 63 years (M = 42.9, SD = 8.52). Household size ranged from 2 to 9 individuals (M = 4.9, SD =2.02) and with the exception of four respondents, all others were living in a household with at least one child under the age of 18 years. All respondents self-identified as major decision makers in their households. Only eight (18.6%) of this sample had completed secondary school, while nine (20.9%) had not completed primary school education. Participants self-identified as Kamba, Kikuyu, Kisii, Luhya, and Luo thereby providing a diverse cultural perspective.

**Data collection and analysis**

Data were collected through four in-depth focus group interviews and a brief six question close-ended survey with each respondent participating in only one focus group discussion. Focus group interviews are especially advantageous as a research method as a heterogeneous group is more likely to elicit lively conversations that lend to comparing and contrasting experiences, thereby providing a nuanced description of the phenomenon.

Interviews were conducted in Kiswahili (national language), English, Kikuyu, and Sheng (slang). The first author is fluent in all of these languages. Focus group interviews were digitally recorded with each groups’ permission, and flip charts used to highlight the key words and major points that emerged throughout each interview session. A research assistant (with certification in human subjects’ research) was also present to assist with facilitation. Transcriptionists were hired to transcribe and translate the data into English. The first author checked all transcriptions and translations to ensure accuracy and consistency.

Data were analyzed using AtlasTi software [38]. A phenomenological data analysis approach was used [33, 34]. To enhance the process, two coders—the first author (coder #1) and the second author (coder #2) independently reviewed the transcripts. It should be noted that coder #1 is Kenyan, has previously analyzed these data for other themes, and has been immersed in this literature for close to a decade while coder #2 is North American and has substantial experience working with qualitative data. To check for and avoid the introduction of assumptions, interpretations, and meanings exogenous to the transcripts as provided by the participants, both coders independently engaged in a neutral appraisal of the transcripts to establish a global understanding of the interviews. This process ensured completeness because each coder would ideally identify meaning units on account of their different theoretical backgrounds, world view and biases. In the second round of analysis, both coders met to discuss the emergent meaning units and to integrate these units into meaningful structures. After several iterations, this part of the data analysis process identified two levels at which corruption of resources takes place, namely provider and institutional levels. The final round of data analysis reconstructed the data further by attempting to understand what these different levels of misappropriation tell us about this population’s experiences. Connecting these two themes to the numerous examples in the data, the coders were able to explain this phenomenon by exemplifying how misappropriation takes place, the consequences on well-being, and suggested solutions to address the identified gaps.

**Results**

The issue of corruption as it relates to the well-being of the groups was mentioned and discussed throughout all four
focus groups. Participants described incidences of resource misallocation, theft, and denial of services across two thematic levels namely at the provider and institutional levels. Under each thematic level, quotations derived from respondents’ perceptions of how corruption manifests in their lives, their interpretation of its impact on overall well-being, and proposed solutions are presented. Table 1 Participants identified a system of service provision, which was fraught with corruption. The discussion further evolved into examples of how the lack of accountability emboldens individuals to either deny services or game the system for personal or collective gain. Focus group participants identify ways in which at the institutional level government agents, international donors, and the research community engage in practices that could be construed as disadvantageous to PLHIV. Finally, participants identify ways in which institutions could provide greater PLHIV protections and ownership of the response system.

Service providers
This section presents narratives discussing experiences with service providers, including health care workers, community workers, and bankers. Given the differences in the roles and functions of facility-based health workers and community-based health workers, data on these two groups are presented separately. In addition, given the Kenyan Government’s integration of economic empowerment interventions as a component of the HIV response system [3] and the critical role income and assets play in the health and well-being of impacted households, participant discussions that revolve around banking representatives are included in this section.

In discussions revolving around facility-based health-care providers, participants described situations where workers denied them services. Specifically, female respondents from Group D discussed how the intersection of HIV, stigma, and tribalism in Kiambu County resulted in a delay of health services. In addition to stigmatization by doctors and other hospital workers, these women described an instance where hospital staff were heard to attribute this delay of service to their tribal affiliation. Here, the women speak of arriving at the hospital early only to have other patients seen before them...

Respondent 1: That one was attended to, then the third one was called, and they kept calling others in for treatment, until they got to the tenth person, and I was just sitting there. I started to ask why I am not being called in yet I was there first. I found my file on the table but it had been kept aside. When I asked, they told me that I was bringing a disturbance, step outside come in only after I have called you in.

Respondent 2: I was there that day and she is not the only one who was affected, I too was affected.

Respondent 1: So I went outside and I overheard the social worker and the doctor, I don’t know who else was in the room but it’s just the people who work there, I overheard them say, “That one is a Luo (tribe), she will have to wait”. I was very hurt. I went in and asked them, “doesn’t a Luo deserve treatment?”

It should be noted that upon further probing, respondents from this group did confirm that this denial of service was due to discrimination based on both their HIV status and tribal affiliations: “here in Thika District, sometimes people are discriminated against because of their tribe”. Group D. In instances such as these, hospital staff prioritized care for patients with a similar tribal affiliation by delaying treatment to patients from different ethnic groups. However, this group also acknowledged that the system is improving and the situation is not as dire as it once was.

Further, participants noted service delivery differences across different service delivery settings. In particular, Group D provided examples to illustrate county variations in public HIV care. It should be noted that theoretically county level services should follow comparable administrative, payment, and care procedures. Participants noted how stark differences in costs and services are unfair, and arouse their suspicions about the proper use and disbursement of national resources that

| Table 1 | Emergent thematic levels |
|---------|-------------------------|
| **Thematic Levels** | **Service providers** | **Institutional** |
| What is experienced | – Theft of resources designated for PLHIV | – Bribing officials to amend/issue legal documents |
| | – Misdirection of resources from PLHIV to the public | – Misdirection of resources from PLHIV to the public |
| | – Denying services due to ethnicity and HIV | – Difficult to access service system |
| How it manifests and affects PLHIV | – Heightens the cost burden of the diagnosis | – Lack of support services |
| | – Longer hospital wait times | – Consumers are denied ownership of the response system |
| | –Hard to access bank loans | Proposed solutions |
| | | – Legal protections of PLHIV Representation within the response system |
| | | – Transparency |
| | | – Representation within the response system |
| | | – Equity |
hospitals receive to serve them. These regional differences are especially pertinent given well documented instances of ‘tribalism’ and regional disparities in national resource allocations [19, 20] previously noted:

Respondent: I am part of a support group in Maragwa. When you go to the clinic in Maragwa, the first thing you are given tea because you arrived early, it is assumed that you have had nothing to eat. If lunch time finds you there you are given lunch. When it’s time to go home you are given two hundred shillings for transport... If you go to the hospital there suffering from the flu, you won’t have to buy medicine. You do not even need to buy a card. However, here where we live, we do not see things like those. They do not reach us. We wonder where they go to.

In addition to regional service delivery differences, variations in the way providers treat PLHIV were noted between public and private care facilities “So I went to the private health center called Mulumba (St. Mulumba) and I am normally treated very well. I was very discouraged at the government run ones” Group D. Although the circumstances surrounding the quality of treatment provided at the public center are unclear, when consumers feel unwelcome, they may not seek needed treatment thereby compromising adherence and retention into care. Participants continued to describe their skepticism about the proper use of resources when they are charged for services that should otherwise be covered by government benefits and therefore offered free of charge to them:

Respondent: Here even to get a card (medical card) you need money.

Respondent: Even if you go there (Thika Hospital) critically ill, you must buy a card before you are attended to.

Respondent: And that’s in a government hospital.

In addition to these auxiliary charges participants were also curious as to why PLHIV are often turned away by providers when they are ill, “another thing in this hospital is, when you go on a Saturday or a Sunday and they see your card has CCC written on it, they tell you to come back on Monday.” Group D. Thus, participants illustrated how the quality, accessibility, and costs of care vary widely despite government efforts to fund and standardize services and also noted variations in the way providers treated PLHIV. Their conversations therefore centered around reasons why PLHIV did not receive comparable treatment across all public centers, and where the resources clearly intended for them were directed.

Community health workers (CHW) are a critical part of the HIV support system in Kenya. Respondents discuss how community workers benefit from concrete supports that are meant for PLHIV, which leads to greater out-of-pockets costs. One participant describes a situation where a CHW stole blankets intended for her children:

Respondent: I want to ask something, these CHW, for example there was a time they asked us to fill forms where I live. The lady asked for a hundred shillings for each child. I gave 300 shillings for my children and returned the form to her. Only one child was issued a blanket, the other two got none, and remember we paid a hundred shillings for each form. As the CHW she said she had people she was caring for and took 3 blankets to take to them. Later she was asked whether she had taken those blankets to the people and it turned out she hadn’t. The blankets were taken from her house by the Headman. She said they would have to wait for her to bring them because she was already using them in her house. You see, they hide these things from the people they are expected to benefit.

Respondent: And that person gets paid to work, they are salaried.

Respondent: They ask us for all this money and they forget we have to work very hard to get it, even go without some things so that they can forward those forms for you. Group B

Participants expressed outrage and disappointment that a paid professional would exploit a patient, especially one who is also experiencing financial struggles. Conversation continued and participants speculated that CHWs might engage in these behaviors because many are not HIV infected and do not relate to the patients they serve. Recruiting and training CHWs from the PLHIV community was proposed as a counter to this exploitation. Participants argued that CHWs who share a diagnosis with their clients might be more inclined to empathize with and therefore provide better services to the community as described by one participant in Group B: “If CHW has HIV it’s okay … they will relate because the person they are helping has HIV too.” Group B.

Economic empowerment is a strategy that has been used in the public and private sectors to address the HIV epidemic. Given the economic burden of a seropositive diagnosis and the high poverty rates in the region, income-generating activities were discussed by all groups as interventions that strengthen this population
both economically and socially. For instance, participants from Group A discussed the merits of their rabbit rearing business which served a threefold purpose: a much needed and affordable protein for group members, a source of income when excess products are sold to local communities, and finally as an activity that keeps the group socially engaged and connected.

Given the preeminence of income in the fight against HIV, financial institutions play a key role in the response system. Participants from groups B, C, and D discussed how proposals written by PLHIV meant to bolster their economic functioning are often un-funded or when funded the resources are directed towards non-affected groups. Participants argue that a sero-positive status, their low-income status, and tribal affiliation is used to discriminate against funding for group projects, “as members we write proposals. But when you write this proposal, you hear that another group benefited but the one that has HIV people questions are asked about how they will repay a loan” Group B. Respondents are indeed committed to securing their economic well-being and do make the necessary efforts to attend the relevant trainings in the hope of receiving financial supports which are not always forthcoming, “we were trained for 6 months and we did not get any support” Group C.

Participants proposed several solutions to the issues they had identified. To reduce discrimination, group members discussed the importance of having a representative voice and equity in the service provision system. Representation is viewed as a way in which agencies can be held accountable during service provision. Specifically, respondents highlight the benefits of including their peers as representatives on these government councils.

Respondent: I would also like us to talk about the government, yes the government is saying that its giving us support but those who have been given the mandate to help us are benefiting themselves.

Respondent: For example the government gives food to those who are HIV positive and those who are supposed to supply the food are selling the food, those who are in charge are not affected like us and the people who are chosen are not HIV positive... In case there is any support that is given we should have representatives... we should know the representatives very well. Group C

The solution of representation was further elaborated when the group members continued their discussion:

**Interviewer:** There should be a representative?

Respondent: Yes, the money should not be distributed by the government.

Respondent: One of us should be involved in the distribution of that money.

Respondent: We should be the ones who are supposed to be given the money.

Respondent: ...we also get people who usually come and tell us to fill forms, give our passport photos, ID and those documents are going to be dumped so we don’t believe anyone.

Respondent: They make money off of us. Group C

Earlier, respondents expressed their belief that providers divert resources away from PLHIV because they do not understand or relate to PLHIV. Thus, respondents assume that by having PLHIV involved in decision making and service provision, providers will be less likely to take or misallocate resources, thereby increasing accountability within the system.

**Institutional level**

At the institutional level participants perceived a system that is permissive of corrupt government officials, misdirection of national resources intended for PLHIV, and a difficult to access response system. One of the ways this manifests is the collusion of government officials with relatives and non-relatives alike to deny PLHIV of critical economic resources. Again, given the strong association between HIV and economic disenfranchisement, the theft and misappropriation of their meager resources is especially detrimental to their well-being. Participants shared a variety of situations where family members and village elders deliberately colluded with government officials to misdirect resources intended for them. Both genders identified women as being especially vulnerable. For example, one participant from Group B describes how relatives bribe legal officials to deny widows access to land upon the death of a husband by altering official documentation: “It comes in because as I have told you, the brother has money, right? You the widow are left without any money. Because of corruption, the said brother will go and give whatever amount of money and after a few minutes, the documents will be given to him with his name written on them”. A participant from the same group added, “Let me contribute a little, for instance, everywhere in this country there is an assistant chief. The assistant chief knows everyone in their area. They know whose wife you are, they know who has died. If the assistant chief is bribed, your case is closed. It starts with the administration, because the administration in the village is the chief and assistant chief. Whether you go to the chief or to the police station, they all work in the same way, together.” Group B
A male participant from group A described an experience he had where he helped a female acquaintance secure legal documents: “There is a lady I went to assist to get a death certificate at the City Mortuary. She had tried to get one for a whole year and every time she would go they would tell her that they already issued one. When I went there… I found out that they had written two death certificates. I asked why they had issued two death certificates, had this person died twice? How can you note two death certificates for one person?” In this instance the document in question was a death certificate, a document which is critical to the succession process and is used to secure household assets after the death of a family member.

Institutional players were further identified as misdirecting national resources intended for PLHIV. For instance, participants from Group D noted in their discussions instances where food and money donations intended for PLHIV were misdirected away from these intended target groups: “There was a time I heard that there are donors who send food to Kenya for people who are living the virus. Who does this food benefit because we don’t get it”. Again, although participants are not a part of the HIV response system, these group members are aware of how resources ought to be allocated and lack of access or receipt of these resources may raise questions about proper allocation and distribution.

How is this corruption at the institutional level experienced by these participants? Participants discussed situations where accountability mechanisms (in place to prevent skimming and false claims) are circumvented and as a result they do not receive potential services and resources. Group C participants describe an instance where they were asked to cooperate with information gathering efforts by a government group seeking external donations. Presumably, the group needed a count of PLHIV to justify their request for funding:

**Interviewer:** When you sign somewhere do you usually ask why you are signing?

**Respondent:** Even if we ask we are going to be cheated.

**Respondent:** We are usually told that there is funds that are about to be released and the donors want to know how (many) members we have, write your name and sign, since you want to get support then you will just sign, since the donor is not there to know the only proof that he can get is by me writing my name and signing and that’s why we have said, it’s good that you have a recorder so that the donors can listen to us and not you, the donors should not give the funding to those who are not affected because they do not give us the funds. Group C

Although participants seemed aware that their cooperation might not yield any direct benefit to them (and in fact, might only serve others’ personal gains), they complied with the request anyway. Given their tremendous financial needs, many felt as though they could not risk not cooperating. Thus, although PLHIV are aware of the potential use of their exploitation for others’ personal gain, they might also often be unwillingly complicit in corruptive behaviors because of their own dire economic statuses. This engenders a feeling of hopelessness, when PLHIV know that the promised assistance may never materialize.

Feelings of mistrust as a result of exploitation were not only reserved for government officials. Participants also detailed their growing mistrust with the research community. They perceive an imbalance in this relationship with the scales tipped towards the researchers’ favor. To protect their own interests, PLHIV have begun demanding monetary compensation prior to consenting to research activities, “…there are a lot of people who call on us...they then tell us it is possible to be helped. Then you live with that hope...then you live waiting and that is the reason why these days when you ask to interview a person living with HIV they ask you for money. Because people have realized that they are being used” Group D. Another group member offered a poignant statement on the disconnect between the data collected by researchers and the resulting interventions that do not seem to have a direct impact on her life, “now, when you interview groups and go back abroad, we the ones you have interviewed are not the ones who benefit from the research. Doesn’t that hurt?”

To address some of these situations participants first identify individual wealth protection mechanisms that they can undertake to protect their economic resources and to circumvent the collusion of family members with corrupt government officials. Participants from all four groups discussed at great lengths some of the strategies they should apply to protect themselves from economic exploitation. These include using the legal system, the use of both oral or written wills, and divulging the location and quantity of household wealth holding to children early on to stave off disinheritance after their deaths.

Participants also proposed several solutions to address the institutional loop holes identified in the system including consumer accountability and having a representative voice at the table. Such an approach would not only deal with the misdirection of services but also promote the availability of services that are targeted and tailored to this population’s specific needs. In the quote below a participant in Group B posed a question to the group pointing towards the need for accountability in
funding streams. “May I ask a question? Is it possible for example when people are writing proposals, there are those who sit down and decide that HIV people need this and this, is it possible two have at least two HIV Positive people in those meetings?” This sentiment is echoed by participants in part of a conversation that was initiated by the interviewer. This discussion points to a level of accountability that PLHIV would inject into the system “if this money was in the custody of people living with AIDS in Kenya, it would get to those who are affected because they know all the difficulties of this disease” Group A.

Participants reported feeling infantilized by the system and want ownership of the research process to ensure that the results address critical problems that they encounter. To do so, respondents noted the importance of community participatory research approaches:

Respondent: when you are doing your research please tell them not to start at the top. When you start at the top it doesn’t reach them (PLHIV), it doesn’t pay

Respondent: It doesn’t reach us. Come to the grass root. Like now you have come to the grass root. If you started at the top you couldn’t know anything

Respondent: Even those projects they (donors) think they can start, they should start from the ground, send their people here, they start from the ground. Group A

Thus by starting “at the top” participants feel as though research studies or other externally initiated projects might not be addressing the critical problems that they encounter and, thus, the results are not likely to benefit them.

Discussion and implications
These findings emerged from a larger study designed to understand intergenerational wealth transmission in families impacted by HIV in Kenya. Perceived corruption emerged as a salient theme during participants’ discussion of their experiences. Given the research team’s responsibility to report findings as entrusted to them by study participants, this particular sub-study further explored consumers’ experiences and perceptions of corruption. Using transparent and rigorous data analysis procedures, perceived instances of corruption were identified among direct care providers in health care and other service systems and at the institutional level among both local and high-ranking public officials. Corruption is widespread and, thus, a high priority concern among people living in sub-Saharan Africa [39]. In this study, participants described the corruption throughout Kenya’s HIV response system in their own words. Corruption manifests as a variety of behaviors among public decision makers, but differs depending on the setting. Within healthcare organizations, other entities that serve PLHIV, and within the larger governmental and international institutions, participants described how they believed that providers diverted medications, food, and other resources intended for PLHIV, charged for services that were perceived to be free, delayed treatment, or outright denied benefits to PLHIV. Many of these actions could have been motivated by public officials’ or health care workers’ personal economic interests; however, in some of the cases described, these officials or workers did not directly benefit. Rather, other patients or citizens from similar tribal groups, or those who are not directly affected by HIV benefitted from their actions by accessing resources or services that may not have been merited. Although corruption is typically motivated by direct personal gains, our study illustrates how corruptive behaviors might also be motivated by the potential to extend such gains to one’s own social group. Based on participant perceptions, in many cases, decision makers might be justifying their actions based on stereotypes about PLHIV or tribal divisions.

Mitigating corruption – implications for intervention
Study findings highlight the potential for several policy or programmatic interventions for mitigating corruption within Kenya’s HIV response system. Chiefly, participants advocated for greater ownership of the HIV response system in the form of PLHIV representation. Members of all four peer support groups involved in this study believe that including PLHIV in decision-making could hold institutions accountable thereby creating a more effective service delivery system. Citizen participation (and specifically participation of other PLHIV) also encourages greater transparency in the way that resources are allocated and services created. Addressing information asymmetries would not only address the current system inaccessibility but would also empower the community. In other countries, transparency measures and opportunities for citizens to have a voice in administrative and policy decisions have empowered citizens to challenge corruption and ultimately improved satisfaction with the health care system [21, 22]. These present findings therefore add to the growing literature that identifies advocacy among individuals and families impacted by HIV and AIDS to be a useful tool in drawing attention to harmful practices in the HIV response infrastructure; consistent with this movement, communities in Kenya demand greater control over programmatic interventions both at the national and local levels.

In addition to greater accountability and transparency within Kenya’s public and private institutions, participants also identified the need for additional support for controlling their assets and economic security. PLHIV
are especially vulnerable to asset loss when they are set to inherit wealth from a family member. Additional legal protections that safeguard PLHIV from property grabbing could ensure participants rightfully inherit assets. In addition, further assistance with inheritance planning could help PLHIV ensure their assets are appropriately directed in accordance with their wishes upon their death. Together, legal protections and financial planning assistance could improve individuals’ control over their assets.

Our findings also highlight ethical and accountability implications for the international community. Participants’ concerns that international aid does not reach them point to the need for international donors to be aware of potential resource diversions and the negative consequences for PLHIV. For instance, USAID developed tools for assessing corruption in country and tailoring anti-corruption strategies [40]. Tools such as these that recognize each society’s unique socio-cultural, political, and economic environment hold promise in addressing this issue. In collaboration with government officials, more proactive fiscal and programmatic monitoring and other accountability structures could help ensure international aid reaches the intended targets. In addition, international researchers studying HIV treatment, service needs, and experiences of PLHIV should consider their local contributions. Consumers have a long history of mistrust with researchers – researchers who win external funding to study the HIV pandemic arrive in-country and gather data directly from PLHIV. Yet, participants rarely see the results. Furthermore, programs and policies are designed based on the interpretation of that data by people outside of the community [26]. Producing ethical and responsible research that fills a local need calls for well-designed scientific participatory approaches.

Finally, anti-corruption measures are unlikely to be successful in Kenya without continued efforts to reduce stigmatization and discrimination based on HIV status and ethnic membership. Given that disclosure of HIV sero-status is integral to procuring resources from service providers (41) pervasive stigmas and stereotypes create a social context that allows decision makers to rationalize corruption [6]. So until misinformation surrounding a HIV diagnosis is eradicated and the individual worth of persons affected by the virus is socially elevated, corrupt acts targeting this population may continue. At the institutional level, appealing to public service motivations and promoting strong ethical values among decision makers [17] will hopefully begin to address this situation.

Limitations
Because this study was not designed with the specific intent of exploring corruption, we acknowledge that we may have missed other facets of this phenomenon. Although participants shared their personal experiences with corruption as service consumers, they might not be privy to observing (or confirming) all forms of corruption, especially behaviors that occur among higher-level administrators and officials. Thus, we recognize that these data do not provide objective evidence of corruption but do provide preliminary evidence of the influence of consumers’ perceptions about corruption on resource acquisition, health service access, and outcomes. In addition, the study design precludes any local or national generalizability on the extent to which corruption occurs or affects PLHIV. However, these perspectives gathered from PLHIV who are well positioned to describe their experiences with the system are vital and should be considered in our scrutiny of the HIV response system. Although corruption is perceived to be widespread throughout Kenya, follow up research is needed to determine the magnitude of the problem, how frequently it occurs, and the resulting impact on PLHIV. In addition, future research is needed that tests the effectiveness of anti-corruption measures targeting government agencies as well as providers in the HIV response system.

Conclusions
Participants place great importance on the theme of corruption as it relates to their overall well-being. This study expands on prior literature documenting the negative consequences of corruption on national economic development and health by illustrating the impact on the daily lives and well-being of PLHIV. Specifically, our findings highlight how corruption in Kenya’s health system and governmental institutions may be driven, in part, by HIV and tribal stigmas. Based on participants’ accounts, corruption throughout the system results in fewer resources for PLHIV. Corruption in the form of resource misappropriation or theft is especially deleterious given the high cost burden already borne by the study population.

Endnotes
1 Comprehensive Care Centers (CCC) are medical centers charged with the delivery of HIV medical services including counseling, nutrition, and other support services.

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Available data and materials
The dataset supporting the conclusions of this article is not included within the article due to the study’s assurances to participants that the raw focus group and demographic information data would not be shared publicly, and that all attempts would be made to maintain confidentiality.

Authors’ contributions
NK designed and conducted the study, led the focus groups, data analysis, and manuscript preparation. AB served as a data coder, assisted with data interpretation, and contributed to manuscript preparation. KW contributed to data interpretation and manuscript preparation. All authors read and approved the final manuscript.

Competing interests
The authors declare that they have no competing interests.

Consent for publication
Not applicable.

Ethics approval and consent to participate
This study was approved by Adelphi University’s Institutional Review Board in 2012. All participants provided their informed consent to participate in this study.

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Research Reports

Coming to Terms With Permanent Involuntary Childlessness: A Phenomenological Analysis of Bulletin Board Postings

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Abstract

Little is known about the role that online support communities play in the lives of women faced with permanent involuntary childlessness. To understand the experiences of these women, this study conducted a thematic analysis of messages downloaded from an online community for permanent involuntary childlessness. Four central themes were identified: Feeling like an “outsider”, A whole lifetime of loss, Coming to terms with childlessness and Finding a safe haven online. These findings show that the online community appeared to empower women to move on with their lives and discover a new sense of self-worth and identity beyond that of motherhood.

Keywords: infertility, online support, involuntary childlessness, social support, internet, psychosocial well-being

Infertility defined as the inability to conceive after two years of regular unprotected sexual intercourse, is estimated to affect approximately 72.4 million people worldwide (Boivin, Buntin, Collins, & Nygren, 2007). A review of the infertility literature suggests that men and women faced with infertility will often experience a strong need for psychosocial support and guidance; a need which is not always adequately met by existing sources of support (Alesi, 2005; Malik & Coulson, 2008a; Schmidt, 2009). Recent research has explored the potential role of the Internet and in particular online support communities, in helping to address these unmet support needs (Epstein, Rosenberg, Grant, & Hemenway, 2002; Epstein & Rosenberg, 2005; Himmel, Meyer, Kochen, & Michelmann, 2005; Malik & Coulson, 2008a).

An online community can be described as a social network that is created and supported by electronic media (Wellman, 1997). Online support communities are typically facilitated through bulletin boards, which allow users to communicate with one another by posting and replying to messages on a discussion board. Some websites may include additional features such as a chat room or private messaging option. These online communities are unique in that they allow individuals to engage in either synchronous or asynchronous written communication with people from all over the world and access a dynamic source of peer and/or professional support, advice and information at virtually any time of the day (Braithwaite, Waldron, & Finn, 1999; Ferguson, 1996).

Research across a range of different health conditions has shown that online support communities can offer individuals a unique and valuable source of social support (Braithwaite et al., 1999; Bunde, Suls, Martin, & Barnett,
In addition, participation in online communities has been linked to several positive psychosocial outcomes including a sense of empowerment, improved quality of life and reduced depression (Bartlett & Coulson, 2011; Evans, Donelle, & Hume-Loveland, 2012; Mo & Coulson, 2010; van Uden-Kraan et al., 2008; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). In relation to infertility, several studies have shown that the anonymity of the Internet and online communities offers individuals a novel opportunity to express their feelings and experiences without fear of embarrassment or stigmatization (Malik & Coulson, 2008a; Malik & Coulson, 2008b). Furthermore, research reveals that online infertility support communities can offer many of the therapeutic and self-help processes that occur in face-to-face support networks and can create a strong sense of camaraderie among participants (Malik & Coulson, 2010a). The benefits of accessing online infertility support communities have been shown to be experienced by both individuals who actively post messages to online communities as well as those individuals who simply access the community to read messages posted by others (Malik & Coulson, 2011). Key psychological benefits of participation include reduced feelings of isolation, informational and emotional support, a sense of hope and positivity and tips/advice on how to cope with the effects of infertility on interpersonal relationships (Gold, Boggs, Mugisha, & Palladino, 2012; Hinton, Kurinczuk, & Ziebland, 2010; Malik & Coulson, 2008b; Malik & Coulson, 2010a; Malik & Coulson, 2011). As such it appears that online support communities offer a viable and beneficial alternative source of support for many people affected by infertility.

However, online infertility support communities are not without their disadvantages. Several studies indicate that online communities may not always fulfill the support needs of people facing permanent involuntary childlessness. Research has shown that women who had experienced treatment failure and were facing permanent childlessness, found it difficult to hear about treatment success from other members of the online community. Reading about other people’s pregnancies resulted in feelings of immense grief, anger, and jealousy and appeared to heighten infertility-related stress (Malik & Coulson, 2008b; Malik & Coulson, 2010b; Malik & Coulson, 2011). Thus, it appears that while women may initially benefit from accessing a network of similar others, there is a risk that those women who do not fall pregnant will become increasingly depressed and isolated overtime, particularly if fellow members have become pregnant while they are facing the prospect of potential permanent childlessness (Verhaak, Smeenk, van Minnen, Kremer, & Kraaimaat, 2005; Verhaak, Smeenk, Nahuijs, Kremer, & Braat, 2007).

Estimates suggest that around 4.2% of women wishing to conceive between the ages of 40 and 55 years remain childless due to unresolved infertility (Oakley, Doyle, & Maconochie, 2008). These women may be at risk for developing depression and long-term emotional problems (Verhaak et al., 2005, 2007). Moreover, a number of studies utilizing both qualitative and quantitative approaches; have indicated a general dissatisfaction with the level of information and support provided by clinics in relation to the decision to end treatment and alternative options such as adoption (Peddie, van Teijlingen, & Bhattacharya, 2005; Schmidt, 1998; Souter, Penney, Hopton, & Templeton, 1998). For example, a qualitative study by Peddie et al. (2005) found that women felt the information provided at their final consultation was inadequate and expressed a need for ongoing support from the IVF unit. In light of this, it is important to ensure that individuals making the transition from fertility treatment to permanent childlessness are able to access adequate support and guidance both online and offline.

To date, much of the research focusing on online support and infertility issues has been conducted in online communities that are dominated by individuals undergoing investigation or treatment for infertility. Consequently, comparatively little is known about the role that online support communities can play in the lives of women faced with permanent involuntary childlessness. More in depth research in this area may help health care professionals gain an insight into how they can create positive online and offline environments, in which women feel they can
access the support that they need. To help address the gaps in our understanding of online women’s support needs at this stage of their infertility journey, we conducted a qualitative analysis of messages posted to an online community dedicated solely to individuals facing permanent childlessness. It was felt that a qualitative approach would allow for a more in-depth and richer insight into the experiences of women using the online community. Consequently, through the qualitative analysis, we sought to understand the “lived” experience of women accessing an online community for unresolved infertility and to explore the role that online support plays in the lives of these individuals. To the best of our knowledge, the current study is one of the first to focus specifically on online communication among women facing permanent involuntary childlessness.

Methods

Sample and Data Collection

The data for this study were messages obtained from the archive of a peer-moderated online community designed solely to support individuals dealing with permanent involuntary childlessness. The online community was identified through conducting a Google search of online support for permanent infertility and selected as it appeared to be one of the largest and most active online communities of this nature. At the point of data collection the online community consisted of one bulletin board, which contained just over 1000 messages in its archive, with new messages being posted on a regular basis (around 5-10 messages per week). To begin with, the 40 most recent discussion threads in the archive were downloaded on 15/12/10. This resulted in 224 messages for data analysis. Following the analysis of these messages, it was felt that the point of data saturation (i.e. no new themes or relevant insights coming to light) had been reached therefore no further messages were collected. The length of the messages ranged from 2-956 words (mean = 122 words). Messages identified the date and time of posting and the senders name and gender followed by the message text. From this information it appeared that all the messages were posted by women and a total of 49 unique sender names were identified. Due to the anonymous nature of an online support community, further personal/demographic data about the sample was not available.

Data Analysis

Messages were analyzed using a thematic analysis, which drew on principles of phenomenological research to understand the “lived” experiences of the senders. Phenomenological research is concerned with gaining a deeper and richer insight into the lived experiences of individuals and understanding the meanings that individuals attach to events and phenomena (Beck, 1994). A phenomenological analysis was thus considered an appropriate and ideal method for describing and interpreting the meanings that women attach to their experiences of involuntary childlessness and accessing an online support community. The practical steps involved in the data analysis process, broadly followed the generic thematic analysis guidelines set out by Braun and Clarke (2006) and involved a collaborative process between the study authors. In the first instance, the lead author read the discussion threads several times to become familiar with the dataset. Following this, salient and interesting features of the data were coded. In the final stage, similar codes were grouped together to form overarching conceptual themes, which captured the women’s experiences as expressed through their bulletin board postings. The data and thematic conceptualization was then reviewed by the second author for validity. Following discussions between the two authors, an agreement was reached around the final thematic framework.
Ethical Considerations

Ethical approval was obtained from the University Research Ethics Committee, in accordance with the ethical guidelines for Internet research published by the British Psychological Society (BPS, 2007). For the present study, issues concerning informed consent, privacy and confidentiality were considered particularly relevant. In light of recommendations from previous authors (e.g. BPS, 2007; Eysenbach & Till, 2001), a relatively large and open access online community (i.e. one that does not require any form of registration or subscription to access and read messages) was selected for research purposes. Since the online support community could be considered “public” in nature, informed consent from individual members was not sought.

However, in accordance with the British Psychology Society ethical guidelines, to further protect the privacy and confidentiality of individuals using the online community, the name of the support community and address of the website from which data was collected has not been disclosed in any dissemination of the work. In addition, all quotations used in the reporting of the results were anonymised and entered into a search engine to ensure the quotes could not be traced directly to an individual posting. In instances where quotes were traceable to the original posting, the quote was paraphrased when reporting the results to ensure privacy and anonymity.

Results

The results of the analysis revealed four emergent themes related to the experiences of women accessing an online support community for permanent involuntary childlessness. These themes were labeled as:

- Feeling like an “outsider”
- A whole lifetime of loss
- Coming to terms with childlessness
- Finding a safe haven online

Feeling Like an “Outsider”

A common experience among women posting to the online bulletin board was a sense of isolation from the “fertile world” and the feeling that they were somehow “different” to other women. Many women talked about how not having children of their own meant that they were forever “on the outside looking in” on their peers becoming mothers and raising families. The knowledge that they would never be admitted into this “mum’s club” evoked a range of strong negative emotions in members of the online community. Emotions commonly expressed in the postings included intense feelings of grief and anguish at the loss of their opportunity to become biological parents, as well as anger that this role had been denied to them.

“I constantly feel like an outsider in this world. Wherever I go or whatever I do, I feel like the odd one out. I work in a female dominated environment with either younger girls having babies or the older women becoming grandparents. There are always happy family photos being passed around, so I do feel 'different' to everyone else.”

Several women also described how being unable to conceive a child of their own, appeared to have changed their outlook on life in general, which served to further separate them from other women around them. For example:

“One of the things I find hardest to deal with is people with a child talking about the next or one planning their first as if they are going to order one and the universe will deliver, at particular age gap, what sex they want and that be most convenient after their holiday so they can enjoy a drink!! But the reason it
bothers me so much is that I've had to learn that life isn't like that when it appears others don't have that lesson taught. It can make me feel singled out for some hardship and it's so unfair.”

Hearing about other people’s pregnancies appeared to be a particularly painful experience for women in the online community and served as a poignant reminder that they were unable to conceive themselves. For many women, receiving news that a friend, colleague or family member was pregnant resulted in a mixture of joy, despair and feelings of jealousy. Such news often prompted members to access the online community, in order to vent their frustration and express these conflicting emotions to people who could empathize with their experiences. In this context, the online community served as a unique environment in which women could alleviate their sense of isolation and connect with other women in similar situations.

“I went over to see a friend yesterday to ‘mourn’ the breakup of my relationship and she announced that she is pregnant. I wouldn't wish this feeling of isolation and hopelessness on anyone, especially a close friend but it felt like a kick in the gut non-the-less....”

Some women also described feelings of distress when they heard stories in the media about motherhood or attended family gatherings, where there were young children present. These experiences heightened their feeling of being “the odd one out” and once again brought home the realization that they would never experience motherhood.

“TV personalities seem to get pregnant at the drop of a hat or they have fertility treatment and it just seems to work first time for them. Reading these stories makes me really upset and angry”.

To protect themselves against reminders of their infertility and feeling like an outsider in social situations, several women reported avoiding certain family gatherings or cutting themselves off from friends who were pregnant or had children. Although this coping strategy was effective in avoiding painful feelings in the short-term, in the long-term it appeared to create a vicious cycle with members feeling more isolated and alienated from society as time went by:

“I have had an in built safety mechanism for years in which I distance myself from any friends/work colleagues/family of child bearing age, hence I was left with very few friends of my own age and have gradually felt more and more isolated.”

“I always dreaded family gatherings and made excuses not to go because i hated feeling like the odd one out whilst everyone around me had children or were expecting them. I tried to protect myself because i found it all too painful but at the same time i have found the feeling of isolation really painful and difficult too”.

One environment in which the women found it more difficult to avoid pregnancies and discussions about children was within the workplace. Several members reported that they had gone to great lengths (e.g., changing jobs) to create a “safe” working environment for themselves. However, this safe haven was often short-lived, for example as one woman describes:

“Hi folks, well here I am again after my few months away whilst I am ‘coping’ (haha) Its that wave again.....after moving job to escape the many pregnancies around me I find 2 of my colleagues are pregnant very unexpectedly. one being in her forties with 2 grown up children and the other on her 4th. my safe space has now crashed!”
This posting elicited a surge of responses from other members of the online community who had also been through similar experiences:

“I do really know what you mean about how that sinking feeling grabs you...and then stays for a length of time. It is seems so unfair that you have changed jobs and thought you were in a safe place...only to have to it thrust upon you again. It happened to me last year too and I remember that blow.”

These messages were used to share common experiences and empathy, and also offer reassurance to the poster that the pain and anguish would lessen with time. In this way, members of the online community created a safe and supportive environment in which infertile women could reach out to one another, every time they felt down or experienced a new wave of negative emotions.

A Whole Lifetime of Loss

Members of the online community described multiple losses as a consequence of infertility. First and foremost, there was the loss of an unborn child and the accompanying loss of their hope of becoming parents. Furthermore, for some members permanent childlessness also seemed to challenge their core identity as women; with several posters questioning their role in a society, which they perceived to be obsessed with childbearing. For example:

“I keep thinking I am moving on as my life has changed so much since we stopped the IVF treatments but I just feel like I am slipping backwards when I want to keep looking forwards with as much of a positive way as I can. Living in a society that expect women to have children”.

As this quote illustrates, a key challenge that many women accessing the online community were faced with was the struggle to create a new identity for themselves following their lost hopes of becoming a mother. The online community provided an accessible forum in which these challenges could be shared and discussed anonymously.

Several women expressed the view that although they might learn to live with their loss, they would never fully recover from the grief that came with it. As one woman describes, unresolved infertility seemed to instigate a “whole lifetime of losses” that she would have to encounter at each stage of her life:

“Does anyone else ever get really angry about not having children? It washes over me every so often and I get really cross and hurt, even after all this time. Not only do we miss out on the babies but it’s a whole lifetime of experiences too. Sorry, just feeling a bit sorry for myself. Xx”.

A key advantage of accessing the online community for many women was receiving validation for these powerful emotions. For example, this feeling was reciprocated by other members of the online community, with another woman posting:

“I do get where you are coming from about missing out on things: first birthdays, 18th birthdays / 21st birthdays, first day at school, learning to drive, passing exams (or not), meeting boyfriends / girlfriends for the first time, Christmasses of course!, seeing them ride a bike for the first time, perhaps going to college or university, weddings of course (and hopefully), grand children of course (and hopefully), birthday parties etc, etc, etc. It is so difficult and I too try to think of the lovely husband I have and my dog, Harvey, and my home and the fact I have a car and occasionally have a lovely holiday, but sometimes that just doesn't do it does it!”

Another life event that appeared to be particularly distressing for members was the realization that they would never become grandparents either. Several members discussed their emotional reactions to news that their peers
were becoming grandparents. These reactions seemed to parallel the pain and jealousy they had initially felt when they heard of other women falling pregnant. However, as some women described, the loss of their opportunity to become grandparents not only served as a reminder that they didn’t have children but was almost like a “second wave” of infertility, where they grieved anew for their unborn grandchildren and were again pushed to seek support and consolation online, which for many women was the only forum in which they could access and communicate with other women living with permanent infertility.

“I could not help observing the sign Grandchild on board in the rear window of a car the other day. I have noticed lots of baby/child/princess etc etc on board but never the grandchild one before. It just made me think that it does not matter what age we are or how we feel there is always something or someone to remind us that not only are we not parents but are never to be grandparents either.”

“Found out last night that my partners sisters daughter has just become pregnant and as I am now in the Grandmother age thought I had got past all these feelings but once again I spent all last evening feeling I should be over this by now and then feeling like crying.”

Thus it seems that for this group of women, involuntary childlessness was experienced as a major and recurring loss throughout their life course.

**Coming to Terms With Childlessness**

Most of the people posting to the online community had been through the “emotional rollercoaster” of several unsuccessful cycles of infertility treatment; before they went from “trying to conceive” to facing the prospect of permanent infertility. Prior to this, these individuals had been wholly consumed with the goal of resolving their infertility crisis, but now suddenly found themselves searching for new life goals that did not involve parenthood.

“It’s funny that when things don’t go according to plan, you just want to hide away and be as invisible as possible. Then it’s incredibly hard to re-emerge and reinvent yourself”.

“I have found that I really struggle to come to terms with it all …the fact that you can do nothing to change it, is very disempowering. I have achieved many things in recent years…yet I often feel that this all is nothing because I cant have a child..”

Many women accessing the online community expressed a strong desire to learn to “accept” their infertility and move on with their lives. However as the quotes above suggest, members generally agreed that this was a long and difficult process, particularly with the constant external reminders of their loss (e.g. seeing other women become mothers or grandmothers). There was also a distinction made between “coping” with infertility and achieving “closure”. For example, several women described how they had experienced periods of “calm” where they were able to temporarily move on with their lives, only to find their emotions spiraling downwards again when they were hit with the reality of permanent childlessness.

“I feel I have lots of stuff that I need closure with and I ache for a time when I can get on with my life without this affecting me all the time….It’s that old chestnut again and I’m fed up of it. Thanks for listening”.

“It comes out of nowhere and knocks you flat. I am currently in a calm period but I know that the wave will hit again”.

“Really thought I’d come to terms with not having children but when I see my sisters/brother and friends with grandchildren, it hits home again. It’s not easy.”
A number of women appeared to experience a sense of guilt that they were still dwelling on their infertility years later and were unable to achieve permanent closure.

“I don’t know where I am going and everything seems so pointless, my hubby is fantastic and is so supportive so I should be grateful for what I’ve got…”

“I thought I had got past all these feelings but once again I spent all last evening feeling I should be over this by now and then feeling like crying.”

Counseling was frequently discussed as one means of achieving closure. The online community was used as a forum in which to share both good and bad experiences of counseling. Members also sought advice from one another about the type of counseling they should have and shared some of their anxieties about the process:

“It is a big step to say those inner thoughts out loud and to someone who may have children has always put me off, so I have found a counselor with experiences in this area and I can only hope that if she has children she does not tell me. Will let you know honestly how I get on. I am very positive about counseling and know it can work wonders if you get the right person at the right time so fingers crossed.”

As this quote highlights, most women posting to the online community seemed to consider seeing a counselor as a positive and cathartic process and actively encouraged other members to explore counseling. However, women also expressed the view that finding the “right” counselor and ensuring that they were ready to openly talk about their infertility issues was crucial.

“I found the process challenging sometimes draining and exhausting, but deeply cleansing too. The therapist was very clever and found ways to push my buttons and get me in touch with my feelings because I’m soo good at pasting a big smile on and telling myself I’m doing great when I’m not”.

The use of self-help strategies was also evident within the messages. Women frequently shared inspirational quotes and poetry with one another and described using cognitive strategies to help change negative thought patterns surrounding their infertility. For example:

“I don’t know about anyone else but I have a collection of inspirational quotes which I read from time to time and find that they really help…I thought it maybe would be good if we could share some of our favorites. So here are three things I find inspirational. I hope you do too.”

“It’s easy to think that others have it easy especially with their made to order kids and feel like the grass is always greener. It’s easier to say than do but I’m working on making my little patch as green as possible so that I can stop and admire it rather than looking longingly at someone else’s patch. There are already times I notice theirs looking a bit rough when they are knackered and close to tears with screaming kids fighting around them”.

In addition, some women spoke of the need to “reinvent” themselves through seeking out new activities and social groups as well as finding a new sense of purpose and meaning to their life. This appeared to be a central part of the process of coming to terms with childlessness and accessing the online support community was often viewed as a first step in this process.

“I’ve found it really helpful spending time with friends I’m making who are in a similar position to me and doing things I enjoy that aren’t child-oriented so I give myself more of a chance to notice what’s positive for me. It’s more of a test faced with poster advert scenes of happy families and at those times I just have to accept it makes me feel sad”.

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Finding a Safe Haven Online

Accessing the online community appeared to play an integral role in helping this group of women cope with permanent childlessness. Through using the online community, women discovered a “safe haven” free from pregnant women and families; which was not so easy to find offline. This, coupled with the shared experiences of group members, created a unique environment in which they felt they could openly discuss their experiences and release any negative or confusing emotions surrounding infertility.

“The online community is a life saver for me - having somewhere to ‘feel’ what I’m feeling – safely…”

Although members of the online community were often unable to offer tangible support or advice in response to such postings, they readily provided an empathic “listening ear”. For example, women would often frame their response to messages with phrases like:

“Wish I could say something more useful but take care and we are thinking of you” or “I’m sorry if I cannot help much but I am thinking of you. That’s the great thing about this place people really do know how hard it is.”

The opportunity to simply vent in a supportive environment was experienced as a cathartic and empowering event. As one woman wrote:

“I feel better already just posting and apologise for having displaced on you guys. Thank you again.”

Receiving empathic responses from other members and reading their experiences of similar issues was also perceived as beneficial. Learning that there were others women who went through the same emotions and experiences served to validate the sometimes confusing and conflicting feelings that member’s experienced as a consequence of childlessness. Many women felt unable to talk about their infertility with friends and family, as it was felt that only people who had experienced it firsthand could fully understand their pain and anguish. Consequently, being able to connect with other women who faced permanent childlessness also helped to alleviate some of the isolation and separateness that women felt in their day-to-day lives.

“This online community is the only place that I feel can come to where I am amongst people who truly understand and I feel able to share my difficult moments”.

“I have been a member of this online community for a long time and am pleased to say that time and the friendship of the members has helped heal my wounds”.

“I know what you mean about being on the outside looking in but with this online community I’m beginning to feel a bit more like I belong somewhere…maybe in time we can say that we are on the inside looking out”.

As these quotes suggest, for most individuals the online community created a sense of belonging that was absent in other areas of their life. Indeed, many of the messages posted within the bulletin board conveyed a strong sense of universality and camaraderie between group members. Several members described the online community as a “family” and regularly posted messages praising one another’s coping efforts and offering words of support and encouragement.

“I can promise you, you will get through this and live to be happy again. You’re not at all hopeless and you are a very brave lady. What I read in your post as I read in soo many of the posts on here is the human spirit kicking away under all the misery, refusing to accept the suffering and fighting to come out of the pain. Very best of luck to you and a massive hug to you”.

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“Thank you for being brave enough to put your feelings down here. It’s true that we do feel on the outside looking in. I feel that everytime I have contact with my brother who has three children.”

“…here’s to all of us here. We may not be mums and das but we are aunties, uncles, step parents, doting pet parents, teachers, carers and role models to the young people in our lives…”

The online community also appeared to play a huge part in women’s efforts to build new lives for themselves post fertility treatment. Some women actively used the online community as a way of building a new social circle for themselves. Where women were unable to meet face-to-face due to geographical distance, the bulletin board was used to strike up friendships with other regular posters. For instance, several women regularly posted off topic messages and conversed with one another about other aspects of their life.

“I would like to meet with other members but every time there has been an event close enough for me to get to I have been working or not free to go. I live in West Essex”.

“I would love to exchange feelings and thoughts if you would like too. I am not living in England at the moment but can easily exchange emails and other messages”.

“For me it’s been really important to start building a new network of friends who are childfree…this online community is obviously a big part of that which is why as much as possible I’ve thrown myself into meeting new members and getting to know them better socially, as well knowing that I have people who understand”.

**Discussion**

The current study is one of the first to focus specifically on online communication among women facing permanent involuntary childlessness. Through a phenomenological analysis of bulletin board postings, this study provides a novel insight into the “lived” experience of individuals who access an online support community for permanent infertility. Moreover, the study demonstrates the important role that online communities can play in the lives of these individuals and in their efforts to come to terms with childlessness.

In line with previous qualitative studies with this population (Daniluk, 2001; Johansson & Berg, 2005; McCarthy, 2008; Schwerdtfeger & Shreffler, 2009; Wirberg, Möller, Hogström, Tronstad, & Lalos, 2007), the analyzed messages show that women experienced involuntary childlessness as a major and recurring loss that pervaded all aspects of their lives; threatening their core identity and sense of self, as well as the central values and meanings that they attached to their life. One theme that was particularly strong across the messages was the sense of immense grief and loss that characterized women’s experiences of permanent involuntary childlessness. The knowledge that they would potentially never become biological mothers appeared to instigate a grief reaction akin to that of bereavement.

Kübler-Ross (1969) proposed a five stage model to describe emotional reactions to loss and the process through which individuals come to terms with the accompanying grief: Denial, Anger, Bargaining (seeking in vain for a solution), Depression, and Acceptance (adapting to the loss and planning for the future). This five-stage model has been applied to a variety of significant life events such as job loss, divorce, terminal/chronic illness and bereavement. However, although the theory captures many of the conflicting emotions that women experience in response to infertility, as Volgsten et al. (2010) argue, the model does not adequately portray the complexities of accepting and adapting to permanent childlessness. Indeed, our findings reveal that permanent infertility was typically suffered as a recurring loss that women felt in varying intensities throughout their life. For example, some
women described times when they felt they had reached a level of acceptance, only to find the anger, grief and
depression return when they were faced with an external reminder of their loss. The chronic and cyclical nature
of their grief was particularly evident for women entering the “grandparent” stage of life. For these women, not
becoming a grandmother like their peers was experienced as both a reminder of their infertility as well a secondary
loss (i.e. that of a potential grandchild).

These findings mirror the results of an earlier qualitative study with women 20 years after unsuccessful infertility
treatment (Wirtberg et al., 2007). The study found that these women were now at the age when their peers were
having grandchildren and were thus having to deal with the concept of “grandchildlessness”. Taken together,
these findings highlight that although permanent infertility is in many ways similar to other major life crises, there
are also several marked differences in the ways in which this grief manifests itself and is experienced by women.
Consequently, traditional models of grief and loss may not always be applicable when supporting women facing
the prospect of permanent involuntary childlessness. In particular, it is important for counsellors and other health
care professionals to be aware of the cyclic nature of women’s grief and the potential need for ongoing support
throughout their lifespan.

Another dominant theme within the messages was the sense of isolation and difference that women experienced
within their social networks and day-to-day lives. Unsurprisingly, the women in this study found it extremely difficult
to deal with talk of pregnancy and childbearing from friends, family and colleagues and often felt the need to
isolate themselves from such reminders of their own childlessness. In this context, the online community became
one of the only venues in which women felt that they could “safely” communicate and connect with other women.
Although similar themes have been identified in previous studies of online infertility support communities (e.g.
Malik & Coulson, 2008b; Malik & Coulson, 2010a), the vast majority of people who access online infertility support
communities are often pursuing some form of treatment for infertility and can thus be described as in a “not yet
pregnant” state (Throsby, 2001). While some of these individuals will become pregnant and make the transition
to parenthood, others will have to come to terms with permanent childlessness (Daniluk, 1997). The bonds and
friendships that women form in online infertility support communities can therefore be short lived and dependent
on the outcomes of their fertility treatment. Furthermore, as previous research has suggested, accessing an online
infertility support community may simply serve to increase the feelings of distress and anguish that individual’s
experience as they lose hope of becoming biological parents (Malik & Coulson, 2008b; Malik & Coulson, 2010b).

The findings of this study highlight the importance of also having online communities dedicated specifically to
people faced with permanent infertility. As our results reveal, the ability to vent, seek support and share thoughts
in a “safe” environment is perceived as a cathartic, unique and an invaluable experience, particularly for those
women who are struggling to find a new sense of identity. Previous research has demonstrated that dissatisfaction
with social support among individuals dealing with permanent infertility is linked to higher levels of depression,
anxiety, and grief (Lechner, Bolman, & van Dalen, 2007). Consequently, being able to access an online support
community to bridge gaps in offline social support can be seen as a positive coping strategy and one that should
be actively encouraged by professionals involved in infertility care.

Our findings further show that moving from “trying to conceive” to permanent childlessness presents a significant
threat to women’s sense of self and in particular their gender role identity. For example, through their bulletin
board messages many women described instances where they had questioned their identity as a woman and the
purpose of their life now that the motherhood status was denied to them. Even though these women expressed
a desire to establish a new personal identity for themselves that was distinct from motherhood, in reality many
women struggled to find meaningful alternative life goals. This is perhaps unsurprising given that culturally, caring
and nurturing for a child is often considered a social norm for a woman and seen as an integral part of her gender
role identity (Daniluk, 1997). Hence, as evidenced in this study, the inability to conceive can carry a hidden stigma
and create feelings of inferiority and being “different” (Dyer, Abrahams, Hoffman, & van der Spuy, 2002; Glover,
McLellan, & Weaver, 2009; Sandelowski, 1988; Slepickova, 2009).

In a similar vein, a qualitative study by Kirkman (2003) suggested that the cultural dominance of the motherhood
narrative was a significant barrier to infertile women revising their life goals. Additionally, the absence of a clear
and collective narrative of the “non-mother”, further complicated women’s ability to make sense of infertility. While,
our study also highlights the complex and difficult nature of women’s struggles to come to terms with childlessness,
the findings suggest that the online community may go some way towards helping this group of women create
a new collective narrative for themselves. The current study’s results concur with previous studies of online support,
which have found that the emotional and informational support exchanged within online communities can have
an empowering effect on individuals (Bartlett & Coulson, 2011; Mo & Coulson, 2010; van Uden-Kraan et al., 2008;
van Uden-Kraan et al., 2009). However, the messages in this study often went beyond the exchange of simple
information and support, with members actively using the forum as a venue in which they could explore new col-
lective identities for themselves and promote one another’s self-worth and sense of purpose in life. This pattern
of findings suggests that for some individuals online communities can potentially play a positive and important
role in the process of coming to terms with involuntary childlessness. Further research is therefore warranted to
examine the long-term outcomes of participation in an online community specifically for permanent infertility. Im-
portantly, future research should seek to explore and compare the adjustment and journey of both women who
seek support online and those women who do not.

Limitations
The current study has a number of potential limitations that should be taken into consideration when interpreting
the findings. Importantly, although the study provides rich data for understanding the challenges and issues that
this particular group of women face, these findings may not be representative of how all women cope with permanent
infertility. For example, very little is known about the demographic profile of members and how representative
these individuals are of infertile women in the wider population. Also, it may be that those women who eventually
resolve their grief discontinue their participation in the community, leaving behind those who continue to have
trouble. Thus, the results may only represent the experiences of a particular subset of infertile women who are
struggling to cope with infertility. In addition, the analyzed messages were only a snapshot of discussions taken
from a single online community, the extent to which these messages are representative of communications in
other online support communities for permanent involuntary childlessness or the same community at other times
remains unclear. Future research should therefore seek to examine messages posted to multiple online support
communities for permanent involuntary childlessness and over a longer period of time, in order to explore the
extent to which similar patterns emerge.

It is also noteworthy that the analyzed messages were all posted by women; consequently the study does not tell
us anything about the online experiences of men dealing with permanent infertility. This mirrors the results of re-
search examining other online infertility support communities, which were also found to be dominated by women
(Malik & Coulson, 2010a). However, research has shown that male partners often feel the need to take on a
supportive role in the couple and suppress their own grief, both during and after unsuccessful infertility treatment.
(Malik & Coulson, 2008a; Volgsten, Svanberg, & Olsson, 2010). In this context, online communities could provide a welcoming environment in which men can anonymously and safely express their grief surrounding unresolved infertility. Future research should therefore seek to understand the male partner’s perceptions towards online infertility support communities, in order to identify whether anything can be done to encourage men to make use of this novel source of support.

**Practice Implications**

The findings of this study highlight the potential valuable role that online communities can play in helping women come to terms with permanent involuntary childlessness. Individuals struggling to cope with the prospect of permanent infertility can therefore be encouraged to access and seek support online. Equally, given the increasing popularity and accessibility of the Internet, it is important for health care professionals to ensure that there are adequate online support resources available to cater specifically for the needs of women with permanent infertility. Women should also be made aware that not all online infertility communities will necessarily meet the support needs of women facing permanent childlessness.

More broadly, the results of this study point to the need for health care professionals to be aware of the complex and recurring nature of infertility grief. Individuals terminating fertility treatment should therefore be given details of available counseling and support services and encouraged to access these as and when they feel the need to. In particular, it is important to ensure that women are provided with the resources and support to help them deal with difficult situations (e.g., the workplace, family events, etc.) and build their self-esteem.

**Conclusions**

In summary, this study provides a novel insight into communication within an online support community specifically for permanent infertility. The findings highlight the powerful and sometimes conflicting emotions experienced by women accessing the online support community and the cyclic nature of their grief. For this group of women the struggle to come to terms with their loss, find a new identity and sense of self-worth seemed to be key driving factors pushing them to seek consolation and support online. Importantly, our results suggest that the online community played a pivotal role in empowering these women to move on with their lives and come to terms with infertility, through providing them with a unique source of emotional support and a comfortable, anonymous environment in which they could make sense of their feelings free from reminders of pregnancy.

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by flower-universal’. Hence (1) will become Q (Q (cd) Q (ef)) (2) Where d and f are flower universal and red universal respectively. It will be read as, ‘a flower- individual is qualified by flower-universal and red colour which is qualified by red-universal’. Similarly the sentence, rakta puspati latā will give a sābdabodha expressible as, ‘a creeper individual is qualified by creeper-universal and flower-individual which is qualified by flower-universal and red colour which is qualified by red-universal’. It can be represented by Q(Q(ab) Q(Q(cd) A(ef))) (3) where a and b are the creeper- individual and creeper-universal respectively. It will be noted that creeper individual holds a special place. It is simply a qualificant and never a qualifier. The other elements are either qualifiers or both qualifier and qualificand. Nyāya calls it the chief qualificand of the sentence.

Thus we find that the knowledge gained from an utterance has a specific form. It is one of the reasons that prevented the Naiyāyikas from placing śabda under inference or perception, in spite of criticism from other schools. The form of the perceptual knowledge arising from seeing a cat on the mat can be either ‘The cat is on the mat’ or ‘The mat is under the cat’. It has no determinate structure. Similarly inferential knowledge from seeing smoke on the mountain can be of the form, ‘The hill has fire’ or ‘There is fire on the hill’. But sābdabodha has a determinate structure. The sentence ‘Cat is on the mat’ has a specific form of knowledge which is expressible as ‘The cat is qualified by its presence on the mat’. Thus knowledge from testimony cannot be assimilated into perception or inference.

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HUSSELR'S NOTION OF OBJECTIVITY:
A PHENOMENOLOGICAL ANALYSIS *

KOSHY THARAKAN

The various issues around which the fundamental controversies in philosophy of social sciences revolve concern the questions whether the method of social sciences is fundamentally similar to or different from that of natural sciences (Monism or Dualism), whether the terms of social scientific understanding pertain to individual agents or trans-individual phenomena (Intentionalism v/s Consequentialism), whether social sciences must commit to a realist ontology (Realism or Anti-realism) and whether the end of social sciences is description/explanation or critique etc. Underlying some of these seminal issues is the question whether social sciences can be objective, if so, how? And if not, why not? My paper deals with some aspects of this basic question from the point of view of the philosophical movement called phenomenology.

Phenomenology, as formulated by Husserl, is an attempt to ground all knowledge in unshakable foundation. The unrelenting search for certitude is the principal theme that underlies his works. Thus, Husserl proceeds from an attack on psychologism to phenomenology so as to describe the necessary structures of the world. Such a project leads him to transcendental subjectivity. Transcendental subjectivity constitutes the necessary structures of the world as correlates of its own intentional acts.

1. The Structure of Intentionality

The doctrine of intentionality of consciousness is the key to understand the notion of objectivity in phenomenological philosophy. According to Husserl,

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consciousness as always directed to some object-consciousness is consciousness of something. Intentionality consists in this directedness of consciousness. Thus, if all conscious acts refer to some objects, Husserl maintains that, object is constituted by the conscious act. The phenomenological analysis of consciousness reveals the noesis-noema structure of experience. Noesis is the objectifying act and noema is the intended object. In other words, noesis and noema correspond to the subject and object poles of experience respectively. Every noesis has its corresponding noema. However, the same object can be apprehended differently. That is to say that the many intended objects may refer to the same object grasped in various intending acts. This implies that there is an underlying unity or identity of different 'noemata' of varying acts. Without this unity we cannot support any claim to objectivity. Now, we may ask how does this unity emerge? An answer to this question points to the phenomenological concept of 'horizon'.

In perception an object is given in a perceptual field or horizon. Any object is perceived from various standpoints. These changes in viewpoint are not accidental with respect to an initial perceptual act. These various perspectives are rather intrinsic to the object. Every actual perception implies an horizon of possible perceptions that are expected to occur. Husserl calls this anticipated set of possible perceptions 'internal horizon' (inner horizon). Apart from this there is 'external horizon' (outer horizon). An object perceived does not appear in isolation. There is no such thing in experience as an isolated object. It always stands in relation to other objects. An object appears amidst other objects simultaneously perceived. This is known as external horizon. To quote Husserl:

In seeing I always 'mean' it with all the sides which are in no way given to me, not even in the form of intuitive, anticipatory presentifications. Thus every perception has 'for consciousness' a horizon belonging to its object .... For consciousness the individual thing is not alone: the perception of a thing is perception of it within a perceptual field. And just as the individual thing in perception has meaning only through an open horizon of 'possible perceptions', insofar as what is actually perceived 'points' to a systematic multiplicity of all possible perceptual exhibits to it harmoniously, so the thing has yet another horizon: besides this 'internal horizon' it has an external horizon precisely as a thing within a field of things; and this points finally to the whole world as a perceptual world.¹

Thus, we have seen that 'noema' has horizon both inner and outer, apart from a nucleus- the central core of meaning or objective sense that invariantly presents in
different acts. But in transcendental perception as against immanent perception the
object is not given completely and absolutely. The object of transcendental perception
is capable only of a series of perspectives or profiles that is not fully determinable.
An element of indeterminacy always hangs on. However, this indeterminacy does
not lend to what Quine calls 'indeterminacy of meaning'. For Quine undetermination
by experience necessarily leads to indeterminacy of meaning. Contrary to this, Huserl says:

Indeed, the indeterminateness necessarily signifies a determinableness which
has a rigorously prescribed style. It points ahead to possible perceptual
multiplicities which, merging continuously into one another, join together to
make up the unit of one perception in which the continuously enduring
physical thing is always showing some new "sides" ... in a new series of
adumbrations. Accordingly, those moments of the physical thing which are
also seized upon .... gradually become actually presented, the indeterminacies
become more precisely determined and are themselves eventually converted
into clearly given determination...3

That is, the unity of sense is accomplished by reason prescribing an idea of complete
givenness as an a priori determination.4 In the course of perceptual process, if the
anticipations implied in previous perception are fulfilled later, unification takes place.
That is to say, if the possible perceptions are actualized, then identification of object
is made possible thereby increasing the determinativeness of the object.

In the noesis-noema structure of intentionality, we have so far analyzed the
noema-the intended object, into nucleus and horizon. Similarly, if we analyse the
noetic act, we can see that 'intending falls into direct visualizing of the object as
well as aiming at its horizon'. Now, this 'aiming at' is always done with reference to
a scheme of anticipations known as 'situations'.5 Situations arise out of the emotive
and valutational modes of intending acts. We cannot ignore the situation as merely
one of subjective traits, since as an attitude in regard to the object it has an important
role in the constitution of the object.

It is clear now, that both the noetic act and noematic aspect of intentionality
are vital in grounding experience. If we neglect the situatedness of intentional act
and concentrate only on the noema, we fall prey to naturalism. On the other hand,
ignoring the noema and attending only to the act loads us to unmitigated relativism.
However, phenomenological analysis shows that both noesis and noema are the
two poles of the same pointer called intentionality of consciousness. Nevertheless, the relation between noesis and noema is not one of equality. As Helmut Kuhn points out, noesis has primacy over noema. According to him, "The very objectivity of object is to be defined in terms of objectivating activity." Moreover, Husserl speaks of the object as constituted by the subjective sources. Then the question is: will it not end up in relativism? The answer lies in the notion of 'Lebenswelt' or 'Life-world'.

2. Life World

Life-world is the world of common experience. It is the world prior to the theoretical attitude. The theoretical attitude which idealizes entities paves the way to objective science. In other words, science is an ideal construct or theoretical superstructure which has its basis in the life-world. Life-world, then is a pre-given world that exists for all in common. It is always taken for granted in all human life, in all human activities. The life-world is a realm of original self-evidences (self-givenness). Every mediate cognition confined to this domain has the sense of possibly perceivable as the thing itself, as self-given. Hence all verifications go back to these modes of self-givenness. The thing itself in this given mode of self-evidence is intersubjectively experienceable and verifiable. It is not a substruction of thought. Thus, we have life-world and objective-scientific world which is obtained by idealization. However, the knowledge of the objective-scientific world is grounded in the life-world. The meaning of science becomes intelligible only when one explores the relatedness of the scientific world to the life-world.

Life-world thus understood, comprises multiplicity and relativity. It is a subjective-relative world. To each one of us the objects in the world at large appear under the varying perspectives, according to one's point of view. Hence the life-world implies a community of individuals who interact with each other. It is a historical community. Thus, a life-world is relative to a certain society at a given moment of its history. However, there may be invariant structure of the life-world. As Husserl says:

No one ever thinks about the predications and truths which precede science, about the 'logic' which provides norms within the sphere of relativity, or about the possibility, even in the case of these logical structures conforming purely descriptively to the life-world, of inquiring into the system of principles that give them their norms a priori.
Husserl's Notion of Objectivity

So as to grasp the essential features of the life-world, Husserl subjects it to a series of *epoché*. The first *epoché* concerns the objective sciences, thereby precluding us to find any common objects of the life-world such as spatial shape, motion, sense quality etc. (these are all concerned with objective sciences). But our bracketing reveals that these are the same structures the life-world has despite its relative features. This general structure itself is not relative.

As life-world the world has, even prior to science, the 'same' structures that the objective sciences presuppose in their substitution of a world which exists 'in itself' and is determined through 'truths in themselves'. These are the same structures that they presuppose as a priori structures and systematically unfold in *a priori* sciences, sciences of the logos, the universal methodical norms by which any knowledge of the world existing 'in itself objectively' must be bound.⁸

Nevertheless, the spatio-temporal world that is prior to the theoretical attitude (the scientific attitude) is not one of ideal mathematical points or the straight lines or planes. The bodies in the life-world are actual bodies. Yet not in the sense of the physicist's actual bodies. In other words, these general features of the life-world, though they share the same names, are not concerned with theoretical idealizations and hypothetical subtractions.

Now we have to make a separation in principle of the a priori of the life world from the objective a priori. This is achieved by the first *epoché* of all objective sciences along with all objective a priori sciences. It provides us the insight that the universal a priori of the objective sciences itself is grounded in a universal a priori of life-world. In the search of the general structure of the life-world, we come across the world as the universe of things, distributed within the world-form of space and time. It is the universal field of all actual and possible praxis as horizon. 'To live is always to live in certainty of the world'. It is to be conscious of the world and of oneself as living in the world. The pregivenness of the world effects a givenness of the individual things. Though things (objects) and world are inseparably united, there is a difference between the way we are conscious of both. We are conscious of things as objects within world-horizon. Each object is an object of the world horizon. We are conscious of this world horizon only as a horizon for existing objects. Thus relativity and multiplicity presuppose the world-horizon. Over and against the seeming relativity of the life-world, it exhibits an invariant structural framework or a conceptual scheme that incorporates the relative and changeable.
Nevertheless, such an attempt to overcome relativism looks trivial. What Husserl achieved is only a formal essence. Hence, Mohanty is right when he says that "What was threatened at the level of contents is thereby gained only at the level of form".  

Husserl himself realizes this. Hence he says: "...the first step which seemed to help at the beginning, that epoché through which we freed ourselves from all objective sciences as grounds of validity by no means suffices". So, Husserl turns to a pre-given world itself. He carries out a universal epoché in which a total transformation of our attitude in the life-world is carried out. Through this universal epoché or transcendental reduction we discover the correlation between the world and world-consciousness. Transcendental reduction liberates one from the internal bond of the pre-givenness of the world to a realm of absolutely self enclosed and absolutely self-sufficient correlation between the world itself and world-consciousness. By world consciousness Husserl means the conscious life of the subjectivity which validates the world. This transcendental subjectivity bestows meaning and ontic validity on the life-world. In other words, transcendental epoché effects absolute correlation between the life-world and transcendental subjectivity. However, Husserl cautions us that transcendental subjectivity is not a point of view or interpretation about the world. Every point or view or interpretation about the world is grounded in the pre-given world. By transcendental epoché the world becomes a phenomenon. Hence, transcendental subjectivity constitutes the world. This universal subjectivity / intersubjectivity is nothing but the mankind. However, the human beings are a component part of the world. This leads to a paradox: humanity as world-constituting subjectivity and yet as incorporated in a world itself. To resolve this paradox we have to look into the constitution of intersubjectivity itself. 'T' as the one who practises the epoché put all other human beings in the epoché including my empirical ego. Then 'T' as transcendental ego, first constitutes a primordial sphere of objects and constitutes in itself the alter-ego. Thus, in me another 'T' achieves ontic validity as copresent with his own ways of being self-evidently verified. The ego by its transcendental functions, exhibits transcendental intersubjectivity in its transcendental communalization and constitutes, in the functioning system of ego poles, 'the world for all'. Each subject, in its transcendental mode, constitutes the world as world for all. Husserl says that:

"...each human being 'bears within himself a transcendental I' - not as a real part or stream of his soul... but rather in so far as he is the self-objectification as exhibited through phenomenological self-reflection, of the corresponding transcendental I."
Husserl's Notion of Objectivity

Here, the paradox gets resolved: we human beings in the natural objective sense do belong to the world as real entities. But at the same time, these real entities themselves are phenomena and as such themselves object poles and subject matter for inquiring back into the correlating intentionalities. By the function of this intentionality alone the human beings have their ontic meaning.

Hence, Husserl, by virtue of transcendental epoche, transforms everything objective into transcendental subjectivity. In other words, objectivity in phenomelogical philosophy resolves into transcendental subjectivity.

In his arguments against relativism in the Prolegomena to Pure Logic, Husserl accuses the relativist of contradicting himself. The relativist makes claims that are supposedly objective truths which are later used to show that those very claims are not possible. In other words, the relativist assumes the nonrelative validity of his own concepts in order to show how any such theory or concept is relative. Do these arguments make Husserl an anti-relativist? David Carr answers in the negative. Carr draws some elements from Husserl's phenomenology which make a relativistic interpretation of Husserlianism phenomenology tenable. As he points out, Husserl's search for 'The Given' - the unmediated objects in intuition - does not supply an irrefutable cognitive link to the external world. Since the perceptual objects in space and time are the most primitive objects, Husserl denies the availability of any sense-data beneath the directly given. Reflection on the sensation does not give any evidence for the existence of the objects but only makes claim about those experiences themselves.

Husserl makes a distinction between the object which is intended and the object as it is intended. This distinction is crucial as there are various ways in which an intention relates to its object. In other words, an object which is intended can be intended differently. From this, it follows that though Husserl holds the unmediated nature of objects, it is only with regard to the mediation by some other object. Husserl allows the mediation by concepts - thus the 'object as it is intended'. This distinction between object which is intended and object as it is intended is further developed into the analysis of 'profiles'. It speaks of the object as always seen from some angle or another. As has been mentioned earlier, the object of transcendental perception is never given fully. From this it follows that our perception of objects or cognitive experience of them is always
perspectival. With regard to the cognitive experience of an object, some other perspective is possible as other possible 'intending-as' is allowed. This leaves the object undetermined by our reference to it as other 'intending-as' make other possible references which has obvious implications of relativism. Moreover, the temporal character of consciousness as conceived by Husserl is prone to a relativistic interpretation. Consciousness is conceived as consisting of distinct phases. Thus the present has past and future with it through 'retention' and 'protension'. The passing experiences are held within the present as a background awareness as the future is anticipated in the present. The same of the present is derived from the past as well as the future anticipation. Now Carr argues that if we assume that each individual has a different experiential part and different concerns from each other, then each one confronts the world of his experience in a way that is unique to him or his community.

However, we cannot brand Husserl a relativist as he holds a teleological concept of history and consciousness. Husserl may well accept these relativistic implications but he overcomes relativism with his notion of intersubjectivity. Intersubjectivity is the coincidence or consensus of simultaneous but different intendings of the same object or state of affairs. Though perceptual evidence does not guarantee intersubjective agreement it nevertheless appeals to it. Further, experience makes it forth coming. The role of communication of what one has perceived is emphasized by Husserl. Such a possibility of being able to communicate and consequently to understand what is being communicated is never ruled out. The very fact that the life-world is constituted by the transcendental intersubjectivity as its intentional correlate gives credence to the possibility of intersubjective agreement.

3. **Phenomenological Philosophy of Social Science**

For Husserl, science, like any other cultural fact is a product of human praxix. It takes shape form the interaction of the members of that professional community. It is an open community in so far as the works achieved by the predecessors are taken up and continued by the successors. Criticisms, confirmations and corrections find their place in the activities of the community. This praxis aims at a justifiable agreement among its practitioners. Here Husserl anticipates the post-positivist philosophies of science.
Husserl's Notion of Objectivity

Husserl criticizes the Galilean style of mathematizing the nature. It misunderstands the objective nature as something hidden from the life-world - a reality that is to be explored beneath the appearances of the life-world. For Husserl, objective nature is a regulative principle - an idea with respect to which members of the scientific community orient their work. The idea gets approximated in theories which are the products of the scientific praxis. By such a regulative principle, the subjectivity and relativity of common experience can be overcome in so far as these ideals guide and direct the specific human activity. For Husserl, to be objective means nothing but to have results attained by mutual criticism that withstand further criticisms.\(^\text{13}\) In other words, objectivity is consensus or coincidence of judgements shared by the members of a community. Now, we have to clarify the nature of this consensus. This consensus or coincidence is explained by the concept of truth. For Husserl, truth is not predicated of judgements but of affairs. It is an assertion of what is the case. This assertion is made possible by the phenomenological concept of 'evidence'. Evidence is a mode of consciousness, a manner in which an object is given to consciousness. The establishment of evidence has nothing to do with mysterious vision, rather it is an achievement of consciousness. It is established in the complex act of synthesis. The synthesis of evidence is a coincidence of empty intention and fulfillment. An intention is empty if we merely intend something as truly existing. In order to have evidence we have to identify it with intuitive fulfillment. Evidence thus becomes the experience of self-givenness of something. Then, truth is an idea of the correspondence between meaning intention and meaning fulfillment.\(^\text{14}\) Nevertheless, Husserl talks about truth as idealized rational acceptability.

In the logical sphere, in the sphere of statement, 'being truly' or 'actually' and 'being' something which can be shown rationally' are necessarily correlated. This holds, moreover, for all modalities of being all doxic positional modalities. Obviously, the possibility of the rational showing referred to here should be understood, not as empirical, but as 'ideal', as an essential possibility.\(^\text{15}\)

Both natural sciences and social sciences grow out of the pre-scientific life-world as cultural accomplishments. Social sciences, or Humanistic sciences, as Husserl calls them, are the 'sciences of the human subjectivity in its conscious relation to the world as appearing to it and motivating it in the world as appearing it in action and passions and conversely it is the science of the world as the surrounding world
of persons. Social sciences thus deal with the mundane intersubjectivity. There is a difference in attitude between natural sciences and social sciences. Natural sciences have the theoretic attitude towards the objective world while social sciences are directed towards universal subjectivity, towards the personal attitude as against the natural scientist's theoretical attitude. Thus, the attitude of the social scientist makes the pre-given life-world as his starting point. (S)he finds himself or herself in a world which surrounds him or her. (S)he is practically determined in different ways by this world and his/her praxis makes the world a new. Hence social sciences cannot be reduced to or entirely modeled on natural sciences.

Nevertheless, as R.J.Bernstein reminds us, we have to distinguish the various dimensions of the activity of the social scientists.17

1. A social scientist, like any other man, is a participant in the everyday life-world. (S)he interprets his/her own actions as well as of others.

2. As a social scientist, like any other scientist, (s)he interacts with his/her professional community.

3. As social scientist per se, (s)he is concerned with a representation and explanation of the structures of the everyday life-world. (S)he then takes a theoretical stance against the practical stance.

To sum up, we may say that the theories / hypotheses / explanations etc. are objective in the sense that they are subjected to intersubjective norms of the scientific community.

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The aim of interpretative phenomenological analysis (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants. The approach is phenomenological (see Chapter 3) in that it involves detailed examination of the participant’s life-world; it attempts to explore personal experience and is concerned with an individual’s personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself. At the same time, IPA also emphasizes that the research exercise is a dynamic process with an active role for the researcher in that process. One is trying to get close to the participant’s personal world, to take, in Conrad’s (1987) words, an ‘insider’s perspective’, but one cannot do this directly or completely. Access depends on, and is complicated by, the researcher’s own conceptions; indeed, these are required in order to make sense of that other personal world through a process of interpretative activity. Thus, a two-stage interpretation process, or a double hermeneutic, is involved. The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world. IPA is therefore intellectually connected to hermeneutics and theories of interpretation (Packer and Addison, 1989; Palmer, 1969; Smith, in press; see also Chapter 2 this volume). Different interpretative stances are possible, and IPA combines an empathic hermeneutics with a questioning hermeneutics. Thus, consistent with its phenomenological origins, IPA is concerned with trying to understand what it is like, from the point of view of the participants, to take their side. At the same time, a detailed IPA analysis can also involve asking critical questions of the texts from participants, such as the following: What is the person trying to achieve here? Is something leaking out here that wasn’t intended? Do I have a sense of something going on here that maybe the participants themselves are less aware of?
We would say that both styles of interpretation are part of sustained qualitative inquiry but that the degree of emphasis will depend on the particularities of the IPA study concerned. The ordinary word ‘understanding’ usefully captures these two aspects of interpretation—understanding in the sense of identifying or empathizing with and understanding as trying to make sense of. Allowing for both aspects in the inquiry is likely to lead to a richer analysis and to do greater justice to the totality of the person, ‘warts and all’. IPA also acknowledges a debt to symbolic interactionism (Denzin, 1995) with its concern for how meanings are constructed by individuals within both a social and a personal world.

IPA has a theoretical commitment to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people’s talk and their thinking and emotional state. At the same time, IPA researchers realize this chain of connection is complicated – people struggle to express what they are thinking and feeling, there may be reasons why they do not wish to self-disclose, and the researcher has to interpret people’s mental and emotional state from what they say.

IPA’s emphasis on sense-making by both participant and researcher means that it can be described as having cognition as a central analytic concern, and this suggests an interesting theoretical alliance with the cognitive paradigm that is dominant in contemporary psychology. IPA shares with the cognitive psychology and social cognition approaches in social and clinical psychology (Fiske and Taylor, 1991) a concern with mental processes. However, IPA strongly diverges from mainstream psychology when it comes to deciding the appropriate methodology for such questions. While mainstream psychology is still strongly committed to quantitative and experimental methodology, IPA employs in-depth qualitative analysis. Thus, IPA and mainstream psychology converge in being interested in examining how people think about what is happening to them but diverge in deciding how this thinking can best be studied.

Indeed, we would argue that IPA’s commitment to the exploration of meaning and sense-making links it quite closely to the original concerns of cognitive psychology in its rejection of the behaviourist paradigm that had thus far dominated the discipline. It is interesting to see how Bruner (1990), one of the founders of the cognitive approach, regrets how it swiftly moved from a central concern with meaning and meaning making into the science of information processing. For more on the theoretical foundations of IPA, see Smith (1996a) and Eatough and Smith (in press).

The aim of this chapter is to provide for the reader new to this way of working a detailed presentation of the stages involved in doing interpretative phenomenological analysis. It gives details of each stage and illustrates them with material taken from a study conducted by the authors. At the same time, it should be recognized that, as is generally the case with qualitative research, there is no single, definitive way to do IPA. We are offering suggestions, ways we have found that have worked for us. We hope these will be useful in...
helping the newcomer to IPA to get under way, but remember that, as you proceed, you may find yourself adapting the method to your own particular way of working and the particular topic you are investigating. We would also point the reader to related writing on interpretive phenomenology (Benner, 1994; Van Manen, 1997).

Constructing a Research Question and Deciding a Sample

As will be apparent, IPA is a suitable approach when one is trying to find out how individuals are perceiving the particular situations they are facing, how they are making sense of their personal and social world. IPA is especially useful when one is concerned with complexity, process or novelty. Box 4.1 illustrates the type of research questions that have been addressed by IPA. Research questions in IPA projects are usually framed broadly and openly. There is no attempt to test a predetermined hypothesis of the researcher; rather, the aim is to explore, flexibly and in detail, an area of concern.

Box 4.1 Examples of psychological research questions addressed in IPA studies

- How do gay men think about sex and sexuality? (Flowers et al., 1997)
- How do people with genetic conditions view changing medical technologies? (Chapman, 2002)
- What is the relationship between delusions and personal goals? (Rhodes and Jakes, 2000)
- How do people come to terms with the death of a partner? (Golsworthy and Coyle, 1999)
- How does a woman’s sense of identity change during the transition to motherhood? (Smith, 1999)
- What model of the person do priests have? (Vignoles et al., 2004)
- How do people in the early stage of Alzheimer’s disease perceive and manage the impact on their sense of self? (Clare, 2003)
- What influences the decision to stop therapy? (Wilson and Sperlinger, 2004)
- What forms of social support are helpful to people in pain? (Warwick et al., 2004)
- How does being HIV impact on personal relationships? (Jarman et al., 2005)

IPA studies are conducted on small sample sizes. The detailed case-by-case analysis of individual transcripts takes a long time, and the aim of the study is to say something in detail about the perceptions and understandings of this particular group rather than prematurely make more general claims. This is
not to say that IPA is opposed to more general claims for larger populations; it is just that it is committed to the painstaking analysis of cases rather than jumping to generalizations. This is described as an idiographic mode of inquiry as opposed to the nomothetic approach which predominates in psychology (Smith et al., 1995). In a nomothetic study, analysis is at the level of groups and populations, and one can make only probabilistic claims about individuals; for example, there is a 70 per cent chance that person x will respond in this way. In an idiographic study, because it has been derived from the examination of individual case studies, it is also possible to make specific statements about those individuals.

IPA researchers usually try to find a fairly homogeneous sample. The basic logic is that if one is interviewing, for example, six participants, it is not very helpful to think in terms of random or representative sampling. IPA therefore goes in the opposite direction and, through purposive sampling, finds a more closely defined group for whom the research question will be significant. How the specificity of a sample is defined will depend on the study; in some cases, the topic under investigation may itself be rare and define the boundaries of the relevant sample. In other cases where a less specific issue is under investigation, the sample may be drawn from a population with similar demographic/socio-economic status profiles. The logic is similar to that employed by the social anthropologist conducting ethnographic research in one particular community. The anthropologist then reports in detail about that particular culture but does not claim to be able to say something about all cultures. In time, of course, it will be possible for subsequent studies to be conducted with other groups, and so, gradually, more general claims can be made, but each founded on the detailed examination of a set of case studies. It is also possible to think in terms of theoretical rather than empirical generalizability. In this case, the readers make links between the findings of an IPA study, their own personal and professional experience, and the claims in the extant literature. The power of the IPA study is judged by the light it sheds within this broader context. A final note on sampling: it should be remembered that one always has to be pragmatic when doing research; one’s sample will in part be defined by who is prepared to be included in it!

There is no right answer to the question of the sample size. It partly depends on several factors: the degree of commitment to the case study level of analysis and reporting, the richness of the individual cases, and the constraints one is operating under. For example, IPA studies have been published with samples of one, four, nine, fifteen and more. Recently there has been a trend for some IPA studies to be conducted with a very small number of participants. A distinctive feature of IPA is its commitment to a detailed interpretative account of the cases included and many researchers are recognizing that this can only realistically be done on a very small sample – thus in simple terms one is sacrificing breadth for depth. Recently the first author has been arguing the case for the single case study (Smith, 2004) and for recent examples of IPA case studies, see Eatough and Smith (2006a, 2006b). In the recent past, five or six has sometimes been recommended as a reasonable sample size for a student
project using IPA. Our current thinking is that for students doing IPA for the first
time, three is an extremely useful number for the sample. This allows sufficient
in-depth engagement with each individual case but also allows a detailed exami-
nation of similarity and difference, convergence and divergence. The danger for
the newcomer is that if the sample size is too large they become overwhelmed
by the vast amount of data generated by a qualitative study and are not able to
produce a sufficiently penetrating analysis. We express an intellectual debt to
George Kelly here (see Bannister and Fransella, 1971; Smith, 1990 and Chapter
2 in this volume). To facilitate accessing an individual’s personal constructs, Kelly
suggested considering three elements at a time, allowing the individual to focus
closely on the relationship between the elements in considering a way in which
two were similar to and different from the third. IPA doesn’t prescribe a tech-
nique in the same way but our thinking is clearly related.

Collecting Data: Semi-structured Interviews as the
Exemplary Method for IPA

IPA researchers wish to analyse in detail how participants perceive and make
sense of things which are happening to them. It therefore requires a flexible data
collection instrument. While it is possible to obtain data suitable for IPA analysis
in a number of ways – such as personal accounts, and diaries – probably the best
way to collect data for an IPA study and the way most IPA studies have been con-
ducted is through the semi-structured interview. This form of interviewing allows
the researcher and participant to engage in a dialogue whereby initial questions
are modified in the light of the participants’ responses and the investigator is able
to probe interesting and important areas which arise. Therefore, we will discuss
semi-structured interviewing in detail in this chapter. For discussion of other data
collection methods either used in or consonant with IPA, see Smith (1990) and
Plummer (2000). It is useful first to contrast the primary features of a semi-
structured interview with those of a structured interview.

The Structured Interview

The structured interview shares much of the rationale of the psychological exper-
iment. Generally, the investigator decides in advance exactly what constitutes the
required data and constructs the questions in such a way as to elicit answers cor-
responding to, and easily contained within, predetermined categories, which can
then be numerically analysed. In order to enhance reliability, the interviewer
should stick very closely to the interview schedule and behave with as little vari-
ation as possible between interviews. The interviewer will aim to:

- use short specific questions
- read the question exactly as on the schedule
• ask the questions in the identical order specified by the schedule
• ideally have precoded response categories, enabling the questioner to match what the respondent says against one of those categories.

Sometimes the investigator will provide the respondent with a set of possible answers to choose from. Sometimes the respondent is allowed a free response, which can then be categorized.

Thus, in many ways, the structured interview is like the questionnaire; indeed, the two overlap to the extent that often the interview is simply the investigator going through a questionnaire in the presence of a respondent the interviewer filling in the answers on the questionnaire sheet based on what the respondent says.

The alleged advantages of the structured interview format are control, reliability and speed. That is, the investigator has maximum control over what takes place in the interview. It is also argued that the interview will be reliable in the sense that the same format is being used with each respondent, and that the identity of the interviewer should have minimal impact on the responses obtained.

The structured interview has disadvantages which arise from the constraints put on the respondent and the situation. The structured interview deliberately limits what the respondent can talk about – this having been decided in advance by the investigator. Thus, the interview may well miss out on a novel aspect of the subject, an area considered important by the respondent but not predicted by the investigator. And the topics which are included are approached in a way which makes it unlikely that it will allow the unravelling of complexity or ambiguity in the respondent’s position. The structured interview can also become stilted because of the need to ask questions in exactly the same format and sequence to each participant.

This section has offered only a brief introduction to the structured interview, the aim being to provide a context in which to place a discussion of semi-structured interviewing. For more on the different types of interview used by researchers, see Brenner et al. (1985) and Breakwell (2006).

Semi-structured Interviews

With semi-structured interviews, the investigator will have a set of questions on an interview schedule, but the interview will be guided by the schedule rather than be dictated by it. Here then:

• There is an attempt to establish rapport with the respondent.
• The ordering of questions is less important.
• The interviewer is freer to probe interesting areas that arise.
• The interview can follow the respondent’s interests or concerns.

These differences follow from the basic concerns of an approach such as IPA. The investigator has an idea of the area of interest and some questions to
pursue. At the same time, there is a wish to try to enter, as far as possible, the psychological and social world of the respondent. Therefore, the respondent shares more closely in the direction the interview takes, and the respondent can introduce an issue the investigator had not thought of. In this relationship, the respondents can be perceived as the experiential expert on the subject and should therefore be allowed maximum opportunity to tell their own story.

Thus, we could summarize the advantages of the semi-structured interview. It facilitates rapport/empathy, allows a greater flexibility of coverage and allows the interview to go into novel areas, and it tends to produce richer data. On the debit side, this form of interviewing reduces the control the investigator has over the situation, takes longer to carry out, and is harder to analyse.

### Constructing the Interview Schedule

Although an investigator conducting a semi-structured interview is likely to see it as a co-determined interaction in its own right, it is still important when working in this way to produce an interview schedule in advance. Why? Producing a schedule beforehand forces us to think explicitly about what we think/hope the interview might cover. More specifically, it enables us to think of difficulties that might be encountered, for example, in terms of question wording or sensitive areas, and to give some thought to how these difficulties might be handled. Having thought in advance about the different ways the interview may proceed allows us, when it comes to the interview itself, to concentrate more thoroughly and more confidently on what the respondent is actually saying. For example, Box 4.2 presents a schedule from a project one of us conducted on kidney disease patients’ response to their illness. The participants are undergoing dialysis treatment for their kidney disease – an extremely demanding treatment regimen which involves going to hospital three or four times a week and being attached to a dialysis machine for about three hours.

### Box 4.2 Interview schedule: patient’s experience of renal dialysis

#### A. Dialysis

1) Could you give me a brief history of your kidney problem from when it started to your beginning dialysis?
2) Could you describe what happens in dialysis, in your own words?
3) What do you do when you are having dialysis?
4) How do you feel when you are dialysing?
   
   **prompt:** physically, emotionally, mentally.

(Continued)
5) What do you think about?
6) How do you feel about having dialysis?
prompt: some people/relief from previous illness/a bind.
7) How does dialysis/kidney disease affect your everyday life?
prompt: work, interests, relationships.
8) If you had to describe what the dialysis machine means to you, what would you say?
prompt: What words come to mind, what images? Do you have a nickname for it?

B. Identity

9) How would you describe yourself as a person?
prompt: What sort of person are you? Most important characteristics: happy, moody, nervy.
10) Has having kidney disease and starting dialysis made a difference to how you see yourself?
prompt: If so, how do you see yourself now as different from before you started dialysis? How would you say you have changed?
11) What about compared to before you had kidney disease?
12) What about the way other people see you?
prompt: members of your family, friends? changed?

C. Coping

13) What does the term ‘illness’ mean to you? How do you define it?
14) How much do you think about your own physical health?
15) Do you see yourself as being ill?
prompt: always, sometimes? Would you say you were an ill person?
16) On a day-to-day basis, how do you deal with having kidney disease (the illness)?
prompt: do you have particular strategies for helping you? ways of coping, practical, mental.
17) Do you think about the future much?

The following list suggests a sequence for producing an interview schedule. This is intended to be only suggestive, not prescriptive. Note also that doing this sort of work is often iterative rather than linear, and you may find your ideas of what the interview should cover changing or developing as you work on the schedule.
1. Having determined the overall area to be tackled in the interview, think about the broad range of issues you want your interview to cover. The three issues in the kidney dialysis project are description of dialysis, effect on the self and coping strategies.

2. Put the topics in the most appropriate sequence. Two questions may help here. What is the most logical order in which to address these areas? Which is the most sensitive area? In general, it is a good idea to leave sensitive topics until later in the interview to allow the respondent to become relaxed and comfortable speaking to you. Thus, an interview on political affiliations might begin with questions on what the different political parties represent, and then move on to the question of societal attitudes to politics before, in the final section, asking about the person’s own voting behaviour – thus leaving the most personal and potentially most sensitive area until last. In the dialysis project, one could say that all the material is sensitive – but then the respondents know the project is about their health condition and have agreed to talk about it. It was decided that talking about the illness itself was the best way into the interview, and to allow discussion of the effect on the respondent’s sense of self to come later.

3. Think of appropriate questions related to each area in order to address the issue you are interested in.

4. Think about possible probes and prompts which could follow from answers that might be given to some of your questions (see below).

### Constructing Questions

A strategy often employed in this type of interviewing is to encourage the person to speak about the topic with as little prompting from the interviewer as possible. One might say that you are attempting to get as close as possible to what your respondent thinks about the topic, without being led too much by your questions. Good interview technique therefore often involves a gentle nudge from the interviewer rather than being too explicit. This aspect of the methodology runs counter to most of the training received for more orthodox psychology methodologies. Thus, you may well find that in the course of constructing your schedule, your first draft questions are too explicit. With redrafting, these become gentler and less loaded but sufficient to let the respondents know what the area of interest is and recognize that they have something to say about it. It may be useful to try out possible questions with a colleague and get some feedback on the level of difficulty and tone.

Sometimes this initial question will be insufficient to elicit a satisfactory response. This may be for various reasons – the issue is a complex one or the question is too general or vague for this particular participant. To prepare for this, you can construct prompts that are framed more explicitly. Indeed, some of your first draft questions may serve as these prompts. You do not have to prepare prompts for every question, only those where you think there may be some difficulty. So, for example, after question 4 in the dialysis schedule (Box 4.2), there is a prompt to remind the interviewer to ask about each of these domains. After question 8, a prompt is provided in case the respondent has difficulty with the main question itself.
Thus, the interviewer starts with the most general possible question and hopes that this will be sufficient to enable the respondent to talk about the subject. If respondents have difficulty, say they do not understand, or give a short or tangential reply, the interviewer can move to the prompt, which is more specific. Hopefully, this will be enough to get the participant talking. The more specific level questions are there to deal with more difficult cases where the respondent is more hesitant. It is likely that a successful interview will include questions and answers at both general and more specific cases and will move between the two fairly seamlessly. If an interview is taken up with material entirely derived from very specific follow-up questions, you may need to ask yourself how engaged the respondent is. Are you really entering the personal/social life world of the participants, or are you forcing them, perhaps reluctantly and unsuccessfully, to enter yours?

*Funnelling* is a related technique. For certain issues, it may well be that you are interested in eliciting both the respondents’ general views and their response to more specific concerns. Constructing this part of the schedule as a funnel allows you to do this. Thus, in Box 4.3, the first question attempts to elicit the respondent’s general view on government policy. Having established that, the interviewer probes for more specific issues. The general point is that by asking questions in this sequence, you have allowed the respondents to give their own views before funnelling them into more specific questions of particular concern to you. Conducted in the reverse sequence, the interview is more likely to produce data biased in the direction of the investigator’s prior and specific concerns. Of course, it is possible that when answering the first question, the respondent may also address the targeted issue and so make it redundant for you to ask the more specific questions.

**Box 4.3 Funnelling**

1) What do you think of current government policies?
2) What do you think of the current government policies towards health and welfare issues?
3) Do you think the government record in this area is okay, or should it be doing anything different?
4) If so, what?
5) It has been suggested that government policy is moving towards one of self-reliance, the welfare system being there only as a safety net for people unable to finance their own provision. What do you think of this as a policy?

Below we provide some more tips on good practice for constructing the interview schedule:
• Questions should be neutral rather than value-laden or leading.
  Bad: Do you think that the prime minister is doing a good job?
  Better: What do you think of the prime minister's record in office so far?
• Avoid jargon or assumptions of technical proficiency. Try to think of the perspective and
  language of the participants in your study and frame your questions in a way they will
  feel familiar and comfortable with.
  Bad: What do you think of the human genome project?
  Better: What do you know about recent developments in genetics?
Obviously, the first question would be fine if one were talking to biologists!
• Use open, not closed, questions. Closed questions encourage Yes/No answers rather
  than getting the respondent to open up about their thoughts and feelings.
  Bad: Should the manager resign?
  Better: What do you think the manager should do now?
It all depends on intent and context, however. It is possible to ask what seems like a
closed question in such a way and at such a point in the interview that it is actually
unlikely to close down the response.

Having constructed your schedule, you should try and learn it by heart before
beginning to interview so that, when it comes to the interview, the schedule
can act merely as a mental prompt, if you need it, rather than you having con-
stantly to refer to it.

|| Interviewing

Semi-structured interviews generally last for a considerable amount of time
(usually an hour or more) and can become intense and involved, depending on
the particular topic. It is therefore sensible to try to make sure that the inter-
view can proceed without interruption as far as possible, and usually it is bet-
ter to conduct the interview with the respondent alone. At the same time, one
can think of exceptions where this would be neither practical nor sensible. For
example, it may not be advisable with young children. The location of the
interview can also make a difference. People usually feel most comfortable in
a setting they are familiar with, as in their own home, but there may be times
when this is not practicable and a different venue will need to be chosen.

It is sensible to concentrate at the beginning of the interview on putting
respondents at ease, to enable them to feel comfortable talking to you before
any of the substantive areas of the schedule are introduced. Hopefully, then,
this positive and responsive ‘set’ will continue through the interview.

The interviewer’s role in a semi-structured interview is to facilitate and
guide, rather than dictate exactly what will happen during the encounter. If
the interviewer has learnt the schedule in advance, he or she can concentrate
during the interview on what the respondent is saying, and occasionally mon-
itor the coverage of the scheduled topics. Thus, the interviewer uses the sched-
ule to indicate the general area of interest and to provide cues when the
participant has difficulties, but the respondent should be allowed a strong role in determining how the interview proceeds.

The interview does not have to follow the sequence on the schedule, nor does every question have to be asked, or asked in exactly the same way, of each respondent. Thus, the interviewer may decide that it would be appropriate to ask a question earlier than it appears on the schedule because it follows from what the respondent has just said. Similarly, how a question is phrased, and how explicit it is, will now partly depend on how the interviewer feels the participant is responding.

The interview may well move away from the questions on the schedule, and the interviewer must decide how much movement is acceptable. It is quite possible that the interview may enter an area that had not been predicted by the investigator but which is extremely pertinent to, and enlightening of, the project’s overall question. Indeed, these novel avenues are often the most valuable, precisely because they have come unprompted from respondents and, therefore, are likely to be of especial importance for them. Thus quite a lot of latitude should be allowed. On the other hand, of course, the interviewer needs to make sure that the conversation does not move too far away from the agreed domain.

Here are a few tips on interviewing techniques.

- **Try not to rush in too quickly.** Give the respondent time to finish a question before moving on. Often the most interesting questions need some time to respond to, and richer, fuller answers may be missed if the interviewer jumps in too quickly.
- **Use minimal probes.** If respondents are entering an interesting area, minimal probes are often all that is required to help them to continue, for example: ‘Can you tell me more about that?’ or ‘How did you feel about that?’
- **Ask one question at a time.** Multiple questions can be difficult for the respondent to unpick and even more difficult for you subsequently, when you are trying to work out from a transcript which question the respondent is replying to.
- **Monitor the effect of the interview on the respondent.** It may be that respondents feel uncomfortable with a particular line of questioning, and this may be expressed in their non-verbal behaviour or in how they reply. You need to be ready to respond to this, by, for example, backing off and trying again more gently or deciding it would be inappropriate to pursue this area with this respondent. As an interviewer, you have ethical responsibilities toward the respondent. For more on interviewing, see Taylor and Bogdan (1998), Breakwell (2006) and Burgess (1984).

## Tape Recording and Transcription

It is necessary to decide whether to tape-record the interview or not. Our view is that it is not possible to do the form of interviewing required for IPA without tape recording. If one attempts to write down everything the participant is saying during the interview, one will only capture the gist, missing important nuances. It will also interfere with helping the interview to run smoothly and with establishing rapport.
Of course, the respondent may not like being taped and may even not agree to the interview if it is recorded. It is also important not to reify the tape recording. While the record it produces is fuller, it is not a complete ‘objective’ record. Non-verbal behaviour is excluded, and the recording still requires a process of interpretation by the transcriber or any other listener.

If you do decide to tape and transcribe the interview, the normal convention is to transcribe the whole interview, including the interviewer’s questions (see Box 4.4 for a sample). Leave a margin wide enough on both sides to make your analytic comments. For IPA, the level of transcription is generally at the semantic level: one needs to see all the words spoken including false starts; significant pauses, laughs and other features are also worth recording. However, for IPA, one does not need the more detailed transcription of prosodic features of the talk which are required in conversation analysis (see Chapter 7). Transcription of tapes takes a long time, depending on the clarity of the recording and one’s typing proficiency. As a rough guide, one needs to allow between five and eight hours of transcription time per hour of interview.

Box 4.4 Sample of transcription from dialysis project

Q  Right, okay, em, so I would like to start with some questions about dialysis, okay? And a very basic one just to start with, can you tell me what you do, physically do, when you’re dialysing?

R  What I actually do with myself while I’m sat there?

Q  Yeah.

R  Well, what I tend to do is, I always have a paper, or I watch TV, you mean actually just sat there?

Q  Yeah.

R  I read the papers, I always take two papers from work or a magazine and read those.

Q  Do you mean work papers or?

R  No, just normal everyday papers cos the problem I’ve got is because I’m right-handed and the fistula (?) is on the right-hand side, which is the one annoyance but I can’t write.

Q  Because you can’t write, yeah.

R  Or else I would be able to, so I read the papers or take as many magazines as I can and I always keep myself busy or watch TV. If I’m getting a good enough sound from the television point I watch the news, I always do it the same way, get in, get on, read the news daily papers, any magazines I’ve got, then if I’ve got a good enough sound on the TV I watch the news from half 6 to half 7, that’s during the week when I’m in there, on the Sunday now I do it on a morning, I just buy a Sunday paper and I always read the paper or read a magazine. Always the same, just so I can keep my mind occupied. I always need to do that.

(Continued)
Q So you are able to concentrate enough to be able to do?
R Yeah. And sometimes if I’m tired I can go to sleep for an hour.
Q Right.
R Or if I’ve run out of papers and sometimes I just shut me eyes for an hour, and I can fall asleep but normally if I can I always make sure I get a magazine or a paper and read that and do something.
Q And that sounds as though you’re, that’s quite a determined routine.
R Yeah.
Q Do you, what’s behind that, what what why do you feel the necessity to be so methodical?
R I think what I try and do is, yeah, so that I treat it as part of normal routine, I think that’s what I do it for, I’m sometimes, I always get a paper from work, the same papers, always try and borrow a magazine and read and keep myself, a way not thinking about it while I’m on, that is why I do it and watch TV, so I don’t think about the machine or I get bored if I’m just sat there doing nothing, but mainly not so I don’t think about it, so I can just think about reading the paper, and I read the paper from top to bottom even if I’ve, I just read everything, it’s the same things in the same papers in the daily paper, but I always read the same things, even if it’s just reading the same things again I read the papers from top to bottom all the way through, and any magazines I always read them and read it from the beginning to the end or watch the TV, always keep myself busy thinking about something rather than that, that’s what I feel I do it for.

| Analysis |

The assumption in IPA is that the analyst is interested in learning something about the respondent’s psychological world. This may be in the form of beliefs and constructs that are made manifest or suggested by the respondent’s talk, or it may be that the analyst holds that the respondent’s story can itself be said to represent a piece of the respondent’s identity (Smith, 2003). Either way, meaning is central, and the aim is to try to understand the content and complexity of those meanings rather than measure their frequency. This involves the investigator engaging in an interpretative relationship with the transcript. While one is attempting to capture and do justice to the meanings of the respondents to learn about their mental and social world, those meanings are not transparently available – they must be obtained through a sustained engagement with the text and a process of interpretation.

The following section describes a step-by-step approach to the analysis in IPA, illustrated with a worked example from a study on the impact of chronic...
benign pain on the participant's self-concept. Chronic benign low back pain is a useful subject for IPA, as the context and personal meanings of the pain to the sufferers are critical to their experience. The example is taken from a project using IPA to try to understand the experience of chronic back pain by patients from one clinic in northern England. Participants were interviewed in the style outlined above and the transcripts subjected to IPA. For more on the study, see Osborn and Smith (1998) and Smith and Osborn (in press).

This is not a prescriptive methodology. It is a way of doing IPA that has worked for us and our students, but it is there to be adapted by researchers, who will have their own personal way of working. It is also important to remember that qualitative analysis is inevitably a personal process, and the analysis itself is the interpretative work which the investigator does at each of the stages. The approach is both similar to different from phenomenology and grounded theory (Chapters 3 and 5) as, hopefully, will become apparent.

A project may take the form of a single case design or involve a number of participants. For the latter, it is advisable to begin by looking in detail at the transcript of one interview before moving on to examine the others, case by case. This follows the idiographic approach to analysis, beginning with particular examples and only slowly working up to more general categorization or claims (see Smith et al., 1995).

### Looking for Themes in the First Case

The transcript is read a number of times, the left-hand margin being used to annotate what is interesting or significant about what the respondent said. It is important in the first stage of the analysis to read and reread the transcript closely in order to become as familiar as possible with the account. Each reading has the potential to throw up new insights. This is close to being a free textual analysis. There are no rules about what is commented upon, and there is no requirement, for example, to divide the text into meaning units and assign a comment for each unit. Some parts of the interview will be richer than others and so warrant more commentary. Some of the comments are attempts at summarizing or paraphrasing, some will be associations or connections that come to mind, and others may be preliminary interpretations. You may also find yourself commenting on the use of language by the participants and/or the sense of the persons themselves which is coming across. As you move through the transcript, you are likely to comment on similarities and differences, echoes, amplifications and contradictions in what a person is saying.

The extract which follows shows this first stage of analysis for a small section of the interview with Martha, who was the first participant in our study:
Int. How long has it been like that?
Aggression
Not who I am – identity
Being mean
Can’t help it – no control
Me doing it but not me
Conflict, tension
Me vs nice
Shame, if you knew – disgust
Fear of being known
M. Since it started getting bad, I was always snappy with it but not like this, it’s not who I am, it’s just who I am if you know what I mean, it’s not really me, I get like that and I know like, you’re being mean now but I can’t help it. It’s the pain, it’s me, but it is me, me doing it but not me do you understand what I’m saying, if I was to describe myself like you said, I’m a nice person, but then I’m not am I, and there’s other stuff, stuff I haven’t told you, if you knew you’d be disgusted I just get so hateful.
Int. When you talk about you and then sometimes not you, what do you mean?
Not always me, part of

himself that is rejected
– hateful, the ‘not me’
Not me = pain, defending
against implications that
it is ‘me’
Helpless
Mean/sour – worse than the
pain
M. I’m not me these days, I am sometimes, I am all right, but then I get this mean bit, the hateful bit, that’s not me.

Int. What’s that bit?
M. I dunno, that’s the pain bit, I know you’re gonna say it’s all me, but I can’t help it even though I don’t like it. It’s the mean me, my mean head all sour and horrible, I can’t cope with that bit, I cope with the pain better.

Int. How do you cope with it?
Tearful/distressed,
avoidant/resistant
Unbearable, shocked at self
M. Get out the way, [tearful] sit in my room, just get away, look do you mind if we stop now, I didn’t think it would be like this, I don’t want to talk any more.

This process is continued for the whole of the first transcript. Then one returns to the beginning of the transcript, and the other margin is used to document emerging theme titles. Here the initial notes are transformed into concise phrases which aim to capture the essential quality of what was found in the text. The themes move the response to a slightly higher level of abstraction and may invoke more psychological terminology. At the same time, the thread back to what the participant actually said and one’s initial response should be apparent. So the skill at this stage is finding expressions which are high level enough to allow theoretical connections within and across cases but which are still grounded in the particularity of the specific thing said. From Martha’s account, related above, the following themes emerged and were noted:

Int. How long has it been like that?
Shameful self – struggle with
unwanted self
Fear of judgement
M. Since it started getting bad, I was always snappy with it but not like this, it’s not who I am, it’s just who I am if you know what I
mean, it's not really me, I get like that and I know like, you're being mean now but I can't help it. It's the pain, it's me, but it is me, me doing it but not me do you understand what I'm saying, if I was to describe myself like you said, I'm a nice person, but then I'm not am I, and there's other stuff, stuff I haven't told you, if you knew you'd be disgusted I just get so hateful.

Int. When you talk about you and then sometimes not you, what do you mean?
M. I'm not me these days, I am sometimes, I am all right, but then I get this mean bit, the hateful bit, that's not me.
Unwanted self rejected as true self

Int. What's that bit?
M. I dunno, that's the pain bit, I know you're gonna say it's all me, but I can't help it even though I don't like it. It's the mean me, my mean head all sour and horrible, I can't cope with that bit, I cope with the pain better.

Attribution of unwanted self to the pain
Defence of original self
Ranking duress, self vs pain

Int. How do you cope with it?
M. Get out the way, [tearful] sit in my room, just get away, look do you mind if we stop now, I didn't think it would be like this, I don't want to talk any more.

This transformation of initial notes into themes is continued through the whole transcript. It may well be that similar themes emerge as you go through the transcript and where that happens the same theme title is therefore repeated.

We have presented the two stages for a small extract above to show the way in which the transformation into themes works. To illustrate this process further, here is another section of the transcript, showing first the initial notes and then the emergent themes:

Resistance to change
Avoidance
Struggle against being
'bad person', depression
Fear of exposure/public knowledge
Mean, unsociable, undesirable
Schadenfreude
Loss of care, bitter against will
Rejected as true self
Confusion, lack of control

M. No, not really, well, you don't want to think you've changed at all, and I don't think about it, you've asked me and I'm trying to think and yeah, I don't want to, but I think I'm not a bad person, perhaps, yeah, it brings you down, and then you end up spoiling things.

Int. How do you mean?
M. No one is going to hear this tape, right?
Int. Like we agreed, anonymous and confidential, you get the tape after I'm done.
M. Right, [pause] the pain makes me mean. I don't want to be, but I get like, mean, I don't care about other people, nothing's funny, and I get mad if they try to be nice, like pity. It's not really me, but it is me if know what I mean, I don't like it but I do it, do you understand, and I end up saying sorry, if I've snapped like, it's the pain it's killing, it does that sometimes.

The emergent themes for this extract were noted in the right-hand margin:
Rejection of change
Avoidance of implications
Struggle to accept new self
Undesirable, destructive self
Shame
Undesirable behaviour ascribed to pain
Lack of compassion
Conflict of selves, me vs not me
Living with a new 'me'  
M. No not really, well, you don’t want to think you’ve changed at all, and I don’t think about it, you’ve asked me and I’m trying to think and yeah, I don’t want to, but I think. I’m not a bad person, perhaps, yeah, it brings you down, and then you end up spoiling things.

Int. How do you mean?
M. No one is going to hear this tape, right?
Int. Like we agreed, anonymous and confidential, you get the tape after I’m done.
M. Right, [pause] the pain makes me mean. I don’t want to be, but I get like, mean, I don’t care about other people, nothing’s funny, and I get mad if they try to be nice, like pity. It’s not really me, but it is me if you know what I mean, I don’t like it but I do it, do you understand, and I up saying sorry, if I’ve snapped like, it’s the pain it’s killing, it does that sometimes.

At this stage, the entire transcript is treated as data, and no attempt is made to omit or select particular passages for special attention. At the same time, there is no requirement for every turn to generate themes. The number of emerging themes reflects the richness of the particular passage.

Connecting the Themes

The emergent themes are listed on a sheet of paper, and one looks for connections between them. So, in the initial list, the order provided is chronological – it is based on the sequence with which they came up in the transcript. The next stage involves a more analytical or theoretical ordering, as the researcher tries to make sense of the connections between themes which are emerging. Some of the themes will cluster together, and some may emerge as superordinate concepts. Imagine a magnet with some of the themes pulling others in and helping to make sense of them.

The preliminary list of themes that emerged from Martha’s transcript and were noted in the right-hand margin are shown in Box 4.5. These were clustered as shown in Box 4.6. In this particular case, it will be seen that all the themes listed were present in the two extracts selected. This is because, in this particular case, we have specifically chosen these two extracts for their richness. They encapsulate each of the important issues in our analysis.

Box 4.5 Initial list of themes

Anger and pain
Struggle to accept self and identity – unwanted self
Lack of control over self
Responsibility, self vs pain
Shameful self – struggle with unwanted self
Fear of judgement
Unwanted self rejected as true self
Attribution of unwanted self to the pain
Defence of original self
Ranking duress, self vs pain
Shame of disclosure
Rejection of change
Avoidance of implications
Struggle to accept new self
Undesirable, destructive self
Shame
Undesirable behaviour ascribed to pain
Lack of compassion
Conflict of selves, me vs not me
Living with a new ‘me’

Box 4.6  Clustering of themes

Undesirable behaviour ascribed to pain
Struggle to accept self and identity – unwanted self
Shameful self – struggle with unwanted self, fear of judgement
Shame of disclosure
Struggle to accept new self
Undesirable, destructive self
Conflict of selves, me vs not me
Living with a new ‘me’
Unwanted self rejected as true self
Attribution of unwanted self to the pain
Defence of original self
Lack of control over self
Rejection of change
Avoidance of implications
Responsibility, self vs pain
Shame
Lack of compassion
Anger and pain
Ranking duress, self vs pain
Shame of disclosure
As the clustering of themes emerges, it is checked in the transcript to make sure the connections work for the primary source material – the actual words of the participant. This form of analysis is iterative and involves a close interaction between reader and text. As a researcher one is drawing on one’s interpretative resources to make sense of what the person is saying, but at the same time one is constantly checking one’s own sense-making against what the person actually said. As an adjunct to the process of clustering, it may help to compile directories of the participant’s phrases that support related themes. This can easily be done with the cut and paste functions on a standard word-processing package. The material can be printed to help with the clustering, and as the clustering develops, so the extract material can be moved, condensed and edited.

The next stage is to produce a table of the themes, ordered coherently. Thus, the above process will have identified some clusters of themes which capture most strongly the respondent’s concerns on this particular topic. The clusters are themselves given a name and represent the superordinate themes. The table lists the themes which go with each superordinate theme, and an identifier is added to each instance to aid the organization of the analysis and facilitate finding the original source subsequently. The identifier indicates where in the transcript instances of each theme can be found by giving key words from the particular extract plus the page number of the transcript. During this process, certain themes may be dropped: those which neither fit well in the emerging structure nor are very rich in evidence within the transcript. The final table of themes for Martha is presented in Box 4.7. Because most of the themes recur in this transcript, the identifier in this case points to a particularly good example of the relevant theme.

**Box 4.7 Table of themes from first participant**

1. *Living with an unwanted self*
   - Undesirable behaviour ascribed to pain 1.16 ‘it’s the pain’
   - Struggle to accept self and identity – unwanted self 24.11 ‘who I am’
   - Unwanted self rejected as true self 24.24 ‘hateful bit’
   - Struggle to accept new self 1.8 ‘hard to believe’
   - Undesirable, destructive self 5.14 ‘mean’
   - Conflict of selves, me vs not me 7.11 ‘me not me’
   - Living with a new self 9.6 ‘new me’

2. *A self that cannot be understood or controlled*
   - Lack of control over self 24.13 ‘can’t help’
   - Rejection of change 1.7 ‘still same’
3. Undesirable feelings

- Shame
- Anger and pain
- Lack of compassion
- Confusion, lack of control
- Ranking duress, self vs pain
- Shame of disclosure

(Continued)

(Continued)

| Avoidance of implications | 10.3 | ‘no different’ |
| Responsibility, self vs pain | 25.25 | ‘understand’ |

- Shame
- Anger and pain
- Lack of compassion
- Confusion, lack of control
- Ranking duress, self vs pain
- Shame of disclosure

(1.16 = page 1, line 16)

Continuing the Analysis with Other Cases

A single participant’s transcript can be written up as a case study in its own right or, more often, the analysis can move on to incorporate interviews with a number of different individuals. One can either use the themes from the first case to help orient the subsequent analysis or put the table of themes for participant 1 aside and work on transcript 2 from scratch. Whichever approach is adopted, one needs to be disciplined to discern repeating patterns but also acknowledge new issues emerging as one works through the transcripts. Thus, one is aiming to respect convergences and divergences in the data – recognizing ways in which accounts from participants are similar but also different.

In the study illustrated here, the superordinate list from Martha’s account was used to inform the analysis of the other transcripts. By remaining aware of what had come before, it was possible to identify what was new and different in the subsequent transcripts and at the same time find responses which further articulated the extant themes. Evidence of the superordinate themes ‘living with an unwanted self’ and ‘undesirable feelings’ emerged in other transcripts in ways which helped to illuminate them further. The first stage of the process with Tony’s transcript follows:

Withdrawal, relief
Change in role, putting on an act
No people = bliss
Miserable but no cost
People = duress
People = cannot be yourself
Front, façade, demands of social role and convention
Pain and relationships, kids affected experience

T. Yeah, you know that Desert Island Discs?
Int. The radio show?
T. I’d love that, don’t get me wrong I’d miss my kids and I don’t mean it, but to be away from people and not have to be something else you’re not, that would be bliss.
Int. You’d be happier that way?
T. Yeah, no, well, no I’d still be a miserable old git but it wouldn’t matter, it’s only when other people come around that it matters, if you can just be yourself it doesn’t matter.

Interpretative Phenomenological Analysis
These initial comments were transformed into the following themes:

- Pain and social context
- Conflict in identity
- Conforming to role despite pain
- Self in public domain
- Managing the self in public
- Destructive social consequences of pain
- Self independent of pain
- Self/identity and relationships define pain experience
- T. Yeah, you know that Desert Island Discs?
- Int. The radio show?
- T. I’d love that, don’t get me wrong I’d miss my kids and I don’t mean it, but to be away from people and not have to be something else you’re not, that would be bliss.

One can see here how the analysis of pain and identity is evolving and, as the analytic process in this example continued, the theme of ‘living with an unwanted self’ and ‘undesirable feelings’ transmuted to become ‘living with an unwanted self in private’ and ‘living with an unwanted self in public’. As we said earlier, the researcher can choose to either use the table of themes from the first transcript to orient the analysis of the subsequent ones, or start the analysis of each case, as though it was the first. If one is working with a very small number of cases, for example, a sample of three as we are now suggesting for students’ first IPA projects, then we would recommend that the latter strategy is adopted. When the number of cases is very small, it is best to start analysis of each from scratch and then look for convergence and divergence once one has done each case separately.

Once each transcript has been analysed by the interpretative process, a final table of superordinate themes is constructed. Deciding upon which themes to focus upon requires the analyst to prioritize the data and begin to reduce them, which is challenging. The themes are not selected purely on the basis of their prevalence within the data. Other factors, including the richness of the particular passages that highlight the themes and how the theme helps
illuminate other aspects of the account, are also taken into account. From the analysis of the cases in this study, four main superordinate themes were articulated. The fourth one, ‘a body separate from the self’, emerged late in the analysis. Consonant with the iterative process of IPA, as the analysis continued, earlier transcripts were reviewed in the light of this new superordinate theme, and instances from those earlier transcripts were included in the ongoing analysis. Box 4.8 shows the identifiers for the themes for the two participants looked at in the chapter. In practice, each of the seven participants in the study was represented for each superordinate theme. Sometimes students are worried because they cannot find convergences between their individual case tables of themes. In our experience, this can be seen as an intellectual opportunity rather than difficulty. It is often possible to see higher level convergences across seemingly disparate cases, and so this process pushes the analysis to an even higher level. The resulting analysis respects both theoretical convergence but also, within that, individual idiosyncrasy in how that convergence is manifest.

## Box 4.8 Master table of themes for the group

| Martha | Tony |
|--------|------|
| **1. Living with an unwanted self in private** |      |
| Undesirable behaviour ascribed to pain | 1.16  | 3.27 |
| Struggle to accept self and identity – unwanted self | 24.11 | 2.13 |
| Rejected as true self | 6.3   | 7.15 |
| Undesirable, destructive self | 5.14  | 2.17 |
| Conflict of selves | 7.11  | 12.13 |
| Living with a new self | 9.6   | 2.14 |
| **2. Living with an unwanted self, in public** |      |
| Shame | 5.15  | 10.3 |
| Lack of compassion | 6.29  | 3.7  |
| Destructive social consequences of pain | 8.16  | 10.9 |
| **3. A self that cannot be understood** |      |
| Lack of control over self | 24.13 | 11.8 |
| Rejection of change | 1.7   | 4.16 |
| Responsibility, self vs pain | 25.15 | 13.22 |
| **4. A body separate from the self** |      |
| Taken for granted | 21.15 | 15.14 |
| Body excluded from the self | 23.5  | 16.23 |
| Body presence vs absence | 18.12 | 19.1  |
Writing Up

The final section is concerned with moving from the final themes to a write-up and final statement outlining the meanings inherent in the participants’ experience. The division between analysis and writing up is, to a certain extent, a false one, in that the analysis will be expanded during the writing phase.

This stage is concerned with translating the themes into a narrative account. Here the analysis becomes expansive again, as the themes are explained, illustrated and nuanced. The table of themes is the basis for the account of the participants’ responses, which takes the form of the narrative argument interspersed with verbatim extracts from the transcripts to support the case. Care is taken to distinguish clearly between what the respondent said and the analyst’s interpretation or account of it. And when one sees the extracts again within the unfolding narrative, often one is prompted to extend the analytic commentary on them. This is consonant with the processual, creative feature of qualitative psychology.

Two broad presentation strategies are possible. In the first, the ‘results’ section contains the emergent thematic analysis, and the separate ‘discussion’ links that analysis to the extant literature. An alternative strategy is to discuss the links to the literature as one presents each superordinate theme in a single ‘results and discussion’ section. In the back pain study, the themes are presented together in one analysis section while a separate section is devoted to exploring their implications in relation to the existing literature. A brief extract is shown in Box 4.9.

Box 4.9  Extract from final write-up of the back pain study

Participants were asked to talk as widely as possible about the different ways their pain had affected or influenced their feelings, attitudes or beliefs about themselves. The participants’ accounts clustered around four superordinate themes: living with an unwanted self, in private; living with an unwanted self, in public; living with a self that cannot be understood; and living with a body separate from the self.

Living with an unwanted self, in private

All of the participants related how, as a consequence of living with their chronic pain, they had experienced a deterioration in their sense of self, and were engaged in a struggle to manage that process. The phrase ‘self-concept’ was not used by the interviewer; the participants were asked to describe in their own words how they felt living with their chronic pain had affected the way they saw
or felt about themselves, ‘as a person’. None of the participants reported any problems understanding this concept, referring to it as ‘me’ and ‘who I am’.

Martha’s account captured much of the participants’ despair in relation to the deterioration in their self-regard, and their struggle to assimilate that aspect of their experience of living with pain into their self-concept. The changes Martha reported were associated with significant distress that, at times, outweighed that caused by the pain sensation, and prompted her to withdraw from social contact for fear of harsh judgement:

\textbf{Int.} How long has it been like that?
\textbf{Martha} Since it started getting bad, I was always snappy with it but not like this, it’s not who I am, it’s just who I am if you know what I mean, it’s not really me, I get like that and I know like, you’re being mean now but I can’t help it. It’s the pain, it’s me, but it is me, me doing it but not me do you understand what I’m saying, if I was to describe myself like you said, I’m a nice person, but then I not am I, and there’s other stuff, stuff I haven’t told you, if you knew you’d be disgusted I just get so hateful.

\textbf{Int.} When you talk about you and then sometimes not you, what do you mean?
\textbf{Martha} I’m not me these days, I am sometimes, I am all right, but then I get this mean bit, the hateful bit, that’s not me.

\textbf{Int.} What’s that bit?
\textbf{Martha} I dunno, that’s the pain bit, I know you’re gonna say it’s all me, but I can’t help it even though I don’t like it. It’s the mean me, my mean head all sour and horrible, I can’t cope with that bit, I cope with the pain better.

\textbf{Int.} How do you cope with it?
\textbf{Martha} Get out the way, [tearful] sit in my room, just get away, look do you mind if we stop now, I didn’t think it would be like this, I don’t want to talk any more.

Martha’s account emphasized the distress she felt as she struggled to manage or comprehend her situation. Martha referred to behaviours and feelings she had about herself since having pain, of being ‘hateful’, that she found disturbing and alarming. They gave her feelings of self-disgust, and a fear that if others were aware of them, they, too, would share that disgust:

M: There’s other stuff, stuff I haven’t told you, if you knew, you’d be disgusted I just get so hateful.

Martha was not explicit about what she does that is so ‘hateful’, but showed that it was sufficiently threatening to warrant its concealment. Her use of the term ‘hateful’ was not explicit, but implied that she felt that, in being ‘mean’, she was both full of feelings of hate toward others, and also worthy of hate by others.

She showed a need to see herself in a positive light, as a ‘nice person’, but struggled to do so. This was reflected in her confusion about her sense of self, and her attempts to separate the undesirable behaviour from her self-concept, and attribute it to the pain:

\textit{(Continued)}
(Continued)

M: It’s not who I am it’s just who I am if you know what I mean, it’s not really me … It’s the pain, it’s me, but it is me, me doing it but not me.

Martha appeared to be engaged in an ongoing process of defending her self-concept to retain a sense of self-worth, but she could not reject completely the implication that her ‘disgusting’ behaviour was not just a function of her pain but also related to herself, ‘I know you’re gonna say it’s all me’. The battle to retain a sense of self-worth in the face of her confusing experience of her deteriorating physical and emotional state, and disability, was more difficult to bear than the sensation of pain itself:

M: It’s the mean me, my mean head all sour and horrible, I can’t cope with that bit, I cope with the pain better.

Conclusion

This chapter has aimed to present the reader with an accessible introduction to IPA. We have outlined a series of steps for conducting a research study using the approach. Doing qualitative research may seem daunting at first, but, ultimately, it is extremely rewarding. We hope you may be encouraged by what we have written to attempt a project using IPA yourself.

Box 4.10 presents three examples of IPA in action.

Box 4.10 Three good examples of IPA

Migration and Threat to Identity

This paper by Timotijevic and Breakwell (2000) explores the impact of migration on identity. Immigrants to the UK from the Former Yugoslavia were interviewed about their perceptions of the countries they had left and the one they had joined and the decision to move. Their accounts point to a rich patterning of identifications. Different people used different category membership strategies in relation to their former home. Some stressed their own ethnic identity at the expense of the greater national Yugoslavian while others identified as Yugoslavian and emphasized their own ethnic group as being an important element in that Yugoslavian identity. Thus the category Yugoslavian was not fixed and could therefore be invoked in different ways as part of the process of asserting ones identity. Their relationship to the UK was similarly complex. The paper neatly captures this multifaceted and dynamic process of identification and relates it to various theories of identity, including identity process theory and social identity theory.
Hepatitis C Infection and Well-being

Dunne and Quayle (2001) conducted focus groups with patients who had iatrogenically acquired Hepatitis C infection – that is they became infected from contaminated blood infusion. The authors make a persuasive case for the use of focus groups here in that they argue the style of group facilitation and the fact that members were connected as members of a patients advocate group meant that the data obtained were still able to tap into personal lived experiences. The paper illustrates how difficult patients find it to make sense of their symptoms before they are given a diagnosis. And when diagnosis comes, their reactions are mixed, partly because with it comes awareness of the seriousness of their condition. The paper also explores the negative impact on their primary social relationships. The authors discuss their results in terms of identity and life career and make links to the extant work of Charmaz and Goffman.

Anger and Aggression in Women

Eatough and Smith (2006b) present a detailed case study of one woman’s account of anger and aggression. It is therefore a useful illustration of IPA’s commitment to the idiographic. The paper aims to show how the individual attempts to find meaning for events and experiences within the context of their life and how this meaning making can be hard and conflictual. The analysis begins by demonstrating how dominant cultural discourses are used to explain anger and aggression. These include hormones, alcohol, and the influence of past relationships on present action. It then goes onto examine how the participant’s meaning making is often ambiguous and confused, and how she variously accepts and challenges meanings available to her. Finally, the analysis shows how meaning making can break down and the consequences of this for the individual’s sense of self.

Further Reading

Smith, J.A. (1996) ‘Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology’, Psychology and Health, 11: 261–71.

This paper provides a summary of the theoretical basis for IPA.

Smith, J.A., Flowers, P. and Osborn, M. (1997) ‘Interpretative phenomenological analysis and health psychology’, in L. Yardley (ed.), Material Discourses and Health. London: Routledge, pp. 68–91.

This chapter illustrates IPA applied to three different areas in the psychology of health.
Smith, J.A. and Eatough, V. (2006) ‘Interpretative phenomenological analysis’, in G. Breakwell, C. Fife-Schaw, S. Hammond and J.A. Smith (eds) Research Methods in Psychology, (3rd edn). London: Sage.

This chapter gives an alternative discussion of the IPA method illustrated with material from a project on anger and aggression.

Eatough, V. and Smith J.A. (in press) ‘Interpretative phenomenological analysis’, in C. Willig and W. Stainton Rogers (eds) Handbook of Qualitative Psychology. London: Sage.

This chapter discusses the theoretical foundations of IPA and considers a range of current issues.
A practical guide to using Interpretive Phenomenological Analysis in qualitative research psychology

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Abstract: Interpretative Phenomenological Analysis (IPA) has become a popular methodological framework in qualitative psychology. Studies based in IPA focus on examining how individuals make meaning of their life experiences. A detailed analysis of personal accounts followed by presenting and discussing the generic experiential themes is typically paired with researcher’s own interpretation, which is an expression of double hermeneutics in practice. IPA relies draws upon phenomenology, hermeneutics, and idiography. This paper presents fundamental principles behind IPA and offers guidelines for doing a study based on this framework.

Qualitative methodology frameworks in psychology

For many decades, the mainstream experimental psychology relied on quantitative methodology based on a model, which involved testing theories by deriving hypotheses from them, which could then be checked in practice via an experiment or observation. The researcher was looking for disconfirmation (falsification) of theory, and by eliminating claims which were not true he or she was believed to move closer to the truth. In contrast to this approach, we have observed a growing development of qualitative research methodologies, based on a different epistemological view. Qualitative researchers are mainly concerned with meaning (e.g., how individuals make sense of the world, how they experience events, what meaning they attribute to phenomena). In other words, they are more preoccupied with the quality of experience, rather than causal relationships. While quantitative studies are generally more concerned with counting occurrences, volumes, or the size of associations between entities (which requires the reduction of phenomena to numerical values in order to carry out statistical analyses), a great deal of qualitative research aims to provide rich descriptive accounts of the phenomenon under investigation. In qualitative research, data is usually collected in naturalistic settings (at home, school, hospital). Both participants’ and researchers’ interpretation of phenomena is taken into account in the process of analysis. An important part of qualitative methodology is epistemological reflexivity, which refers to questions such as: How does the research question define and limit what can be found? How does study design and method of analysis affect

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1 This paper was written in English by the two authors and then translated into Polish by the first author.
2 Silverman (1993:1) explains the difference between “methodology” and “method”: whereas the former refers to ‘a general approach to studying research topics’, the later denotes ‘a specific research technique’ (e.g., an in-depth interview, focus group, participatory observation, etc.).
Handbooks in qualitative methodology in psychology usually describe a number of major methodological approaches, such as the Grounded Theory, Phenomenology, Discourse analysis, Narrative Psychology, Participatory Action Research (Smith 2008; Willig 2008; Camic, Rhodes & Yardley 2003). Each type constitutes a comprehensive framework which includes theoretical underpinnings behind it and guidelines for research design (sampling, methods of data collection and analysis). When producing the final report (or a research paper), it is especially convenient to use an established methodological framework. This is valuable, as most journals impose limitations on paper lengths. The researcher can make reference to standardized methods and methodologies, instead of giving detailed descriptions of analytical procedures. This allows more space to present abundant qualitative material. In this paper, we shall describe one of such methodological frameworks, which has become increasingly popular in European and American psychology, namely Interpretative Phenomenological Analysis (IPA). After a short outline of its theoretical orientation, we shall describe the specifics of research problems suitable for IPA, methods of sampling and data collection, and present guidelines for analysis using examples, and final comments on how to produce a final paper. For the reader who is interested, a much fuller treatment of these issues can be found in the book on IPA (Smith, Flowers, Larkin 2009).

IPA theoretical orientation

The primary goal of IPA researchers is to investigate, how individuals make sense of their experiences. It is assumed that people are as ‘self-interpreting beings’ (Taylor, 1985), which means that they are actively engaged in interpreting the events, objects, and people in their lives. To examine this process, IPA draws upon the fundamental principles of phenomenology, hermeneutics, and idiology.

Phenomenology, developed by Edmund Husserl, as an eidetic method, is concerned with attending to the way things appear to individuals in experience. In other words, it aims at identifying the essential components of phenomena or experiences which make them unique or distinguishable from others. By the use of eidetic reduction, phenomenologists try to recognize what essential components make a given phenomenon special (or unique). Phenomenological studies will thus focus on how people perceive and talk about objects and events, rather than describing phenomena according to a predetermined categorical system, conceptual and scientific criteria. This involves ‘bracketing’ one’s preconceptions and allowing phenomena to speak for themselves.

Husserl’s thought was further developed by his follower - Martin Heidegger (1962) into existential philosophy and hermeneutics. Heidegger was concerned with the ontological question of existence itself. According to hermeneutics (from the Greek word ‘to interpret’ or ‘to make clear’) one needs to comprehend the mind-set of a person and language which mediates one’s experiences of the world, in order to translate his or her message (Freeman, 2008). Thus, IPA researchers attempt to understand what it is like to stand in the shoes of subject (although recognising this is never completely possible) and through interpretative activity make meaning comprehensible by translating it (just like the mythological Hermes translated the gods’ messages to humans). This means, that the IPA study is a dynamic process with an active role of the researcher which will influence the extent to which they get access to the participant’s experience and how, through interpretative activity, they will make sense of the subject’s personal world. The analytical process in IPA is often described in terms of a double hermeneutic or dual interpretation process, because firstly, the participants make meaning of their world and secondly, the researcher tries to decode that meaning - make sense of the participants’ meaning making (Smith & Osborn, 2008). In other words, IPA researchers try to understand what an experience (object or an event) is like from the participant’s perspective. Yet, at
the same time, they try to formulate critical questions referring to the material, such as: What is the person trying to achieve here? Is there anything meaningful being said here, which was not intended? Do I have a sense of something going on here that the person himself or herself is perhaps less aware of? IPA studies may thus contain elements of both types of interpretation, making the analysis richer and more comprehensive.

To sum up, IPA synthesizes ideas from phenomenology and hermeneutics resulting in a method which is descriptive because it is concerned with how things appear and letting things speak for themselves, and interpretative because it recognizes there is no such thing as an uninterpreted phenomenon.

The third theoretical orientation which PA relies upon is idiography. It refers to an in-depth analysis of single cases and examining individual perspectives of study participants, in their unique contexts. The fundamental principle behind the idiographic approach is to explore every single case, before producing any general statements. This contrasts with the nomothetic principles which underlie most empirical work in psychology, in which groups and populations are studied to establish the probability that certain phenomena will occur under specific conditions. IPA relies on idiography, meaning that researchers focus on the particular rather the universal (Smith, Harré, & Van Langenhove, 1995). The researcher can make specific statements about study participants because the analysis is based upon a detailed case exploration. IPA researcher will thus start with examining an individual and producing a case study or will move to an equally attentive exploration of the second case, and so on. This idiographic commitment is unusual even among qualitative methodologies. Be it the case, that the researcher wants to study a group of individuals, he or she will move between important themes generated in the analysis and exemplify them with individual narratives (how particular individuals told their stories), comparing and contrasting them (i.e., showing similarities and differences.

**Formulating research questions**

Most qualitative methodology rejects formulating hypotheses prior to research conduct. Instead, it promotes an open inductive approach to data collection and analysis. IPA emphasises studying people idiomatically. It aims at generating rich and detailed descriptions of how individuals are experiencing phenomena under investigation. Its concern with the in-depth exploration of their lived experiences and which how they are making sense of those experiences helps define the type of question which is suitable for an IPA study. Example research problems might be:

- What does jealousy feel like?
- How do young people experience the transition from school to college or university?
- How do people make the decision whether or not undergo chemotherapy?

There are interesting examples of using IPA in psychological research to explore a variety of problems, such as: the relationship between body image, gender and sexual orientation (Morgan & Arcelus, 2009), how people with multiple sclerosis think about the experience of exercise (Borkoles et al., 2008), how being HIV positive impacts personal relationships (Jarman, Walsh & de Lacey, 2005), what influences the decision to stop psychotherapy (Wilson & Sperlinger, 2004), how individual’s sense of identity is affected by being diagnosed with Alzheimer’s disease (Clare, 2003), by homelessness (Riggs & Coyle, 2002) or how it changes during the transition to motherhood (Smith, 1999), how people come to terms with the death of a partner (Golsworthy & Coyle, 1999), or how gay men think about sex and sexuality (Flowers, Smith, Sheeran & Beail, 1997).

IPA was initially applied to problems in health psychology but became more and more popular in other fields. It can be a suitable approach in clinical psychology and psychotherapy to examine
cases. Its strengths can also be utilized in cultural or indigenous psychology, which focus on the *emic* perspective of participants. It can also support psychologists of religion to analyse spiritual experiences or religious rituals and meaning attributed to them. Community psychologists, as well as psychologists of migration and acculturation can find it handy to examine how various groups construct their ethnic (or group) identity, what meaning they attribute to social roles, and how they perceive phenomena. These are just a few examples of how this methodological framework can be used to design qualitative psychological research.

**Sampling in IPA**

The main concern in IPA is to give full appreciation to each participant’s account (case). For this reason, samples in IPA studies are usually small, which enables a detailed and very time consuming case-by-case analysis. At an early stage, the researcher must decide whether he or she wants to give a comprehensive and in-depth analysis about a particular participant’s experiences or present a more general account on a group or specific population. Doing both is rarely possible, so the final goal will determine the subsequent methodology and research design. It is inappropriate to use a large sample size just because that is more common in psychological studies. With IPA, we aim at producing an in-depth examination of certain phenomena, and not generating a theory to be generalised over the whole population. (However, comparing multiple IPA studies on a particular problem may provide insights into universal patterns or mechanisms.)

There is no rule regarding how many participants should be included. It generally depends on: 1. the depth of analysis of a single case study, 2. the richness of the individual cases, 3. how the researcher wants to compare or contrast single cases, and 4. the pragmatic restrictions one is working under. The last category includes time constrains or access to participants. For example, one of us participated in a study to investigate the experiences of parents who had a child with a Juvenile Huntington’s disease - a seemingly rare condition (Smith et al., 2006). The total number of people for whom this is a relevant experience is small and therefore this immediately determines the boundaries for a possible sample. More commonly the potential participant pool is wider and a process of sample selection will need to be undertaken.

IPA studies have been published with, for example one, four, nine, fifteen participants. Larger sample sizes are possible but less common. According to Turpin *et al.* (1997) the clinical psychology doctoral programmes in Britain recommend that having six to eight participants is appropriate for an IPA study. Having a sample as such gives an opportunity to examine similarities and differences between individuals. At the same time, the amount of qualitative data gathered is not overwhelming. In general, IPA researchers should concentrate more on the depth, rather than breadth of the study. A detailed analysis of a single case may be well justified if rich and meaningful data has been collected, which allows the researcher to present original problems, mechanism, or experiences. This will offer an opportunity to learn a lot about the individual, his or her response to a specific situation, and consider connections between different aspects of the person’s account (Smith, 2004). In most studies, however, IPA researchers rely on a small sample rather than a single individual.

Typically, IPA researchers aim for a fairly homogeneous sample (contrary to grounded theorists, for example, who engage in constant comparisons and seek exceptions or odd cases which helps them produce a multidimensional dynamic theory of how different factors affect human behaviours). In IPA, psychological similarities and differences are usually analysed within a group that has been defined as similar according to important variables. Obviously, it is inappropriate to think in terms of random or representative sampling when one is interviewing so few participants. In line with the theoretical underpinnings of IPA, participants are selected purposively. This allows one to find a defined group for whom the research problem has relevance and personal significance. How
homogeneous the group will be depends on two factors: 1. interpretative concerns (degree of similarity or variation that can be contained in the analysis of the phenomenon), and 2. pragmatic considerations (ease or difficulty of contacting potential participants, relative rarity of the phenomenon). The subject matter can itself define the boundaries of the relevant sample (e.g., if the topic is rare and few representatives are available, such as the Juvenile Huntington Disease mentioned earlier). In other cases, when the topic is more commonplace, the sample may include individuals with similar demographic or socio-economic status profiles (e.g., elderly, female members of a specific religious community or young, male patients diagnosed with a particular illness, etc.). In this respect, IPA can be compared to ethnographic studies in which small communities are closely investigated to produce detailed descriptions and commentaries about their culture, where claims are bound to that culture or only cautiously suggested at a broader level. Nevertheless, through a steady accumulation of similar studies on other groups, generalizations may become possible over time (Smith, Harré, & Van Langenhove, 1995).

**Collecting data**

The primary concern of IPA researchers is to elicit rich, detailed, and first-person accounts of experiences and phenomena under investigation. Semi-structured, in-depth, one-on-one interviews are the most popular method to achieve that, although other alternatives of data collection can also be used (e.g., diaries, focus groups, letters or chat dialogues). Semi-structured interviews allow the researcher and the participant to engage in a dialogue in real time. They also give enough space and flexibility for original and unexpected issues to arise, which the researcher may investigate in more detail with further questions.

It is crucial, that researchers have developed their interviewing skills. Apart from mastering active listening and the ability to ask open-ended questions free from hidden presumptions, the interviewer should know to build rapport and gain trust of the participant. A kind of ‘warm-up discussion may be necessary to reduce the interviewee’s tension and get him or her ready to discuss more sensitive or personal issues. With semi-structured interviews, it is helpful to prepare an interview plan in advance. It is merely a guide to facilitate a natural flow of conversation. It can include key questions or areas the researcher wants to discuss (see an example in Frame 1). Formulating specific questions (e.g., relating to sensitive issues) may be helpful for less experienced interviewers. Apart from open and expansive questions which encourage participants to talk at length, it may be also be convenient to think about prompts. These may be helpful if participants find some questions too general or abstract. Questions suitable for an IPA study may concentrate on exploring sensory perceptions, mental phenomena (thoughts, memories, associations, fantasies), and specifically individual interpretations. During an interview, the researcher should also feel comfortable with moments of silence, to allow both oneself and the participant reflect issues being discussed. Furthermore, an experienced interviewer is also sensitive to and tries to be aware of all verbal, non-verbal, and non-behavioural communication.

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3 It involves listening attentively, trying to understand what is being said, negotiating meaning when things seem unclear, ambiguous or abstract, and constructing appropriate questions which helps explore what is being said.
Example interview questions for a study on illness behaviours in an ethnic minority group. The researcher’s goal was to examine how the indigenous culture and acculturation in northern India affected Tibetan patients’ explanatory models and reactions to becoming ill.

1. Can you tell me about your illness experiences when living in exile?
   Prompts: What kind of health problems did you have? How did that feel in your body? How did you interpret symptoms? Why do you think symptoms appeared at that time of your life? What was going on in your mind then? (thoughts/associations/fantasies)

2. What did you think could help you feel better at that time?
   Prompts: What kind of treatment did you think was most appropriate? Why? What did you think should be done to help you overcome your problem(s)? How did you think your condition would change if had done nothing about it?

3. What was your first/subsequent reaction(s)?
   Prompts: How did you decide to go about your health problems? Where did you seek help? / What stopped you from seeking help? If sought medical/non-medical treatment: What did you think about recommendations you received? What was similar or different in what you thought about your problem and how the person you referred to assessed it?

For ethical reasons, and because IPA studies are frequently concerned with significant existential issues, it is crucial that the interviewer monitors how the interview is affecting the participant. Experienced interviewers can easily determine when the participants avoid talking about certain issues, start feeling awkward, ashamed or become very emotional. Using counseling skills may then be useful and if the interviewer has not developed such competence, he or she should follow specific ethical procedures (e.g., stop the interview and refer the person to a professional in mental care). Even though such situations are rare, the researchers should consider all possible risks.

The duration of most IPA interviews is one hour or longer. The semi-structured form of interviews allows the interviewer to ask questions in a convenient order, which may differ from one interview to another. Novel perspectives or topics, which have not been anticipated, may also arise and the researcher is free to develop them. In IPA it is necessary to audio record the interviews and produce a verbatim transcription of it.

Analysis of the qualitative material

Analysing qualitative material using the IPA framework can be an inspiring activity, although complex and time-consuming. It is recommended that the researchers totally immerse themselves in the data or in other words, try step into the participants’ shoes as far as possible. IPA aims at giving evidence of the participants’ making sense of phenomena under investigation, and at the same time document the researcher’s sense making. The researcher is thus moving between the emic and etic perspectives. The latter is achieved by looking at the data through psychological lens and interpreting it with the application of psychological concepts and theories which the researcher finds helpful to illuminate the understanding of research problems. Showing the emic perspective protects researchers from psychological or psychiatric reductionism On the other hand, by looking at data from the outsider’s perspective, we have a chance to develop higher level theories and insights (which the respondent himself or herself may have no access to). The researcher should be careful, however, when applying theories developed in one setting (e.g. western culture) to explain phenomena from a different one. Indigenous psychologists stipulate, that such theories might be irrelevant.

In general, IPA provides a set of flexible guidelines which can be adapted by individual researchers, according to their research objectives. However, these guidelines are merely an illustration of one possible way of analysing the qualitative material. They should not be treated as a recipe and the researcher is advised to be flexible and creative in his or her thinking. To demonstrate how the analysis unfolds, we shall describe the analytic stages of an example study on how Tibetans acculturating in northern India make meaning of their medical conditions.
**Multiple reading and making notes**

The initial stage involves close reading of the transcript a number of times. If an audio recording is available, it is also recommended to listen to it a few times. This helps researchers immerse themselves in the data, recall the atmosphere of the interview, and the setting in which it was conducted. Each reading and listening to the recording may provide some new insights. At this stage, the researcher can make notes about his or her observations and reflections about the interview experience or any other thoughts and comments of potential significance. They may focus on content (what is actually being discussed), language use (features such as metaphors, symbols, repetitions, pauses), context, and initial interpretative comments. Some comments associated with personal reflexivity may also be generated (e.g., how might personal characteristics of the interviewer, such as gender, age, social status, etc. affect the rapport with the participant). It is useful to highlight distinctive phrases and emotional responses. An example of making notes has been demonstrated in Frame 2.

| Original transcript | Exploratory comments |
|---------------------|----------------------|
| **Interviewer:** Can you tell me about the situation you were ill last time? | Attributes good fortune to the Dalai Lama. A cliché or reflects his beliefs? Attributes illness to spirits: does not know the word “penis” or ashamed to use it? Grew worried about his symptoms as they got worse Finds different explanations for his problem Sees symptoms as punishment by nagas |
| Oh, it was long ago. By the grace of His Holiness the Dalai Lama I haven’t had any problems recently. When I arrived here ten years ago… well… even I had a small, like… spirit harm. My [points out to his genitals], you know, my organ got swollen and it was itching. I did not pay attention to it at first, but after a few days it got worst. I had… sort of pain when I was trying to pee, and I was really worried. | Holds folk beliefs about the serpent deities (nagas), ways of offending them (peeing, cutting a tree), and being cursed. Associating skin problems with nagas’ activity |
| **Interviewer:** Why do you think that symptom appeared? | Smiled and seemed embarrassed to talk about sleeping with a woman. What is embarrassing for him – talking about sexual activity, prostitutes? |
| Well, you know, many reasons possible. What I thought at that time and what I think now – two different reasons. I mean, you know, we used to piss everywhere, you see. In a spring, on a tree… we used to pee near that and sometimes my organ [penis] swells. And when I go to lama, he say: “This is harm of nagas because you did something wrong.” So, they would tell me to do this prayer and I do. | Referring to the germs theory to explain his symptoms. How does he go about conflicting explanations? |
| **Interviewer:** Can you tell me how you interpreted your health problem? | |
| Well, at that time, I thought that it was the curse of nagas. These serpent deities, are very powerful beings, you know, so you have to… you know, be careful not to offend them. Sometimes, they… you can see them in a form of a frog or snake. They live in forests, in streams or in a tree. So, you know… when you pee into the stream or on that tree… or cut this tree, you can make them angry and they curse you. Then, you know… skin problems. | |
| **Interviewer:** What else might have caused your problem? You mentioned another reason. Well… it is like… you know, I may have slept with another woman, who may have some problems. Like a prostitute for instance. I think, if that is the cause, then I should go to a doctor. It depends. Maybe naga or maybe… you know… bacteria. Sometimes we have these talks, you know… a nurse or a doctor comes… and they talk about bacteria. “Wash your hands” – you know, after using toilet or “Use condoms.” | |

Frame 2: An extract from an interview with Lobsang (a Tibetan from Dharamsala) about making meaning of his symptoms, with researcher’s notes.

**Transforming notes into Emergent Themes**

At this stage, the researcher should work more with his or her notes, rather than with the transcript. When detailed and comprehensive have been produced in the earlier stage, they should reflect the source material. The aim is to transform notes into emerging themes. The researcher tries to formulate a concise phrase at a slightly higher level of abstraction which may refer to a more psychological conceptualization. Nevertheless, this is still grounded in the particular detail of the participant’s account. At this stage, we are inevitably influenced by having already annotated the transcript as a whole, which is a good example of the hermeneutic circle discussed earlier (the part is interpreted in relation to the whole and the whole is interpreted in relation to the part). Frame 3 shows examples of the emergent themes for the same interview extract with Lobsang.
**Original transcript**

**Interviewer:** Can you tell me about the situation you were ill last time?
Oh, it was long ago. By the grace of His Holiness the Dalai Lama I haven’t had any problems recently. When I arrived here ten years ago… well… even I had a small, like… spirit harm. My [points out to his genitals], you know, my organ got swollen and it was itching. I did not pay attention to it at first, but after a few days it got worse. I had… sort of pain when I was trying to pee, and I was really worried.

**Interviewer:** Why do you think that symptom appeared?
Well, you know, many reasons possible. What I thought at that time and what I think now – two different reasons. I mean, you know, we used to piss everywhere, you see. In a spring, on a tree… we used to pee near that and sometimes my organ [penis] swells. And when I go to lama, he say: “This is harm of nagas because you did something wrong.” So, they would tell me to do this prayer and I do.

**Interviewer:** Can you tell me how you interpreted your health problem?
Well, at that time, I thought that it was the curse of nagas. These serpent deities, are very powerful beings, you know, so you have to… you know, be careful not to offend them. Sometimes, they… you can see them in a form of a frog or snake. They live in forests, in streams or in a tree. So, you know… when you pee into the stream or on that tree… or cut this tree, you can make them angry and they curse you. Then, you know… skin problems.

**Interviewer:** What else might have caused your problem? You mentioned another reason.
Well… it is like… you know, I may have slept with another woman, who may have some problems. Like a prostitute for instance. I think, if that is the cause, then I should go to a doctor. It depends. Maybe nagas or maybe… you know… bacteria. Sometimes we have these talks, you know… a nurse or a doctor comes… and they talk about bacteria. “Wash your hands” – you know, after using toilet or “Use condoms.”

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**Emerging themes**

| Conditions associated with good health and luck |
|-----------------------------------------------|
| Accumulation of positive karma in the past |
| Involvement in actions to accumulate merits |
| Attributing good fortune to lama’s blessing |
| Meaning attributed to spiritual involvement |

| Rationalizing symptoms of illness |
|----------------------------------|
| The concept of negative karma |
| Referring to indigenous beliefs to conceptualize illness |
| Imbalance of humours |
| Attributing illness to supernatural forces |
| Using western conceptualizations to explain illness |
| Attributing symptoms to viruses or bacteria |
| Illness attributed to stress |
| Illness attributed to poor diet |
| Illness attributed to exhaustion |

| Holding conflicting explanatory models |

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**Frame 3: Examples of developing Emergent Themes.**

**Seeking relationships and clustering themes**

The next stage involves looking for connections between emerging themes, grouping them together according to conceptual similarities and providing each cluster with a descriptive label. In practise, it means compiling themes for the whole transcript before looking for connections and clusters. Some of the themes may be dropped at this stage, if they do not fit well with the emerging structure or because they have a weak evidential base. A final list may comprise of numerous superordinate themes and subthemes (see: Frame 4). Researchers who use the traditional method of pen and paper, and write comments and themes in the margin, will probably like to end up with a list of major themes and subthemes, and relevant short extracts from the transcript, followed by the line number, so that it is easy to return to the transcript and check the extract in context. On the other hand, researchers who are using modern software for qualitative data administration, will feel convenient with a mere list of themes and subthemes, as they can produce short descriptions of each theme and use links to appropriate passages in the transcript. Using QDA software with IPA is another subject, however, which needs further elaboration in a separate paper.

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**Frame 4: An example of clustered themes**
Writing up an IPA study

The painstaking analysis described above leads to writing a narrative account of the study. This usually involves taking the themes identified in the final table and writing them up one by one. Each of them needs to be described and exemplified with extracts from interview(s), followed by analytic comments from the authors (see an example in Frame 5). The table of themes opens up into a persuasive account that explains to the reader the important experiential things that have been found during the process of analysis. Using interviewees’ own words to illustrate themes has two functions: 1. It enables the reader to assess the pertinence of the interpretations, and 2. It retains the voice of the participants’ personal experience and gives a chance to present the emic perspective. The final paper will thus include both the participant’s account of his or her experience in his or her own words, and interpretative commentary of the researcher. The narrative account may engage several levels of interpretation, from low-level interpretation of data to a highly detailed, interpretative and theoretical level, which may generate new insights.

In a typical IPA project, the narrative account is followed by a discussion section which relates the identified themes to existing literature. Reflection on the research can be included here, as well as comments on implications of the study, its limitations, and ideas for future development.

Trying to rationalize the onset of his illness, Lobsang initially referred to the traditional indigenous beliefs of the culture he represented:

I thought that it was the curse of nagas. These serpent deities, are very powerful beings, you know, so you have to… you know, be careful not to offend them. Sometimes, they… you can see them in a form of a frog or snake. They live in forests, in streams or in a tree. So, you know… when you pee into the stream or on that tree… or cut this tree, you can make them angry and they curse you.

Stories about serpent deities have been part of everyday life and social discourse in the Tibetan diaspora. They were imbedded in their cosmological system and reflected the belief in the invisible sphere of existence, inhabited by gods, demi-gods, spirits or hungry ghosts. This defined Lobsang’s spirituality and his sense of identity. This also represents shared values Lobsang identified with, such as respect towards nature and all living creation. Yet, in another part of his discourse, Lobsang refers to fundamental principles of tantric Buddhism according to which all phenomena are perceived as “mere reflections of the mind.” As such, serpent deities, powerful, dangerous, and potentially oppressive for those who cross the taboo, can represent inner objects which are projected and used to control the behaviour of body, speech, and mind. Peeing into the stream or cutting a tree which belongs to the nagas carries significant symbolic force…

Frame 5: A brief illustration of writing up an IPA study

Conclusion

Doing an IPA study is a demanding enterprise, despite a possible illusion that using a small sample makes it easy. Obviously, the researcher needs to combine a wide repertoire of skills. To gather valuable data, some degree of interviewing experience is indispensable. Careful, systematic, and rigorous analysis, on the other hand, requires patience and openness to see the world through someone else’s eyes and the ability to control a temptation to a priori impose conceptual categories. The inductive character of most qualitative methodologies requires that theories are derived from data, and not the other way round.

Training in qualitative research in psychology is still relatively new and underdeveloped. Students are thus likely to approach qualitative research with a mindset developed from much fuller training in quantitative methodology. Many feel challenged by the lack of appropriate skills required here. As qualitative psychology matures, we expect the general level of student work to become stronger, deeper, and richer (Smith, 2011).
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