

Positive Guidance and Uncertainty: responding to the career guidance needs of people living with HIV/AIDS

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The introduction of new drug treatments has opened up the prospect of improved health and prolonged life expectancy for many people living with HIV/AIDS (PLWHA). For some this has led to a renewed energy and enthusiasm to consider their future, explore opportunities and make life choices. This paper draws on the findings of a longitudinal research study which evaluated an initiative set up to provide PLWHA with training, education, volunteering and self development opportunities. Their accounts point to the complex issues facing PLWHA, including the impact of health uncertainty on their decision making. The authors suggest that living with continuing uncertainty, which for some PLWHA has resulted in a step by step approach to planning, has implications for the provision of initial guidance and ongoing support.

Introduction

Career guidance is reaching a wider range of clients than ever before, which presents practitioners with different and challenging demands (Collin, 2000). Guidance practitioners working in different contexts are acquiring new skills and taking a reflective approach to both their practice and its theoretical underpinnings in order to respond appropriately to the differing and changing needs of their clients. If evidence-based strategies for guidance are to be developed, these will need to be based on research of relevance to particular client groups. Guidance practitioners working with adults may have clients who are living with HIV/AIDS, yet there appears to be a lack of research undertaken or disseminated widely outside HIV agencies which can be used to inform career guidance practice. This paper seeks to present issues for consideration by guidance practitioners, including those who are taking on the role of Personal Adviser within the Connexions service, who may be working with PLWHA.

People living with HIV/AIDS (PLWHA) form a group of clients who may be at risk of or experience exclusion from opportunities for self development, the labour market and society. The reasons for this are many, including society's stigmatisation of HIV manifest, for example, in employers' reluctance to employ those who are HIV positive. Reliance on benefits can also exclude some PLWHA from opportunities to socialise and partake in self-development activities. Psychological reactions to HIV diagnosis can include fear, guilt, loss of self-esteem, reduced confidence, and insecurity, which can further result in exclusion and isolation. Decisions associated with treatment also present challenges, including dealing with the risks and uncertainties associated with rebuilding lives. These may be further complicated for adults by the consequences of experiencing long-term unemployment (Anderson & Weatherburn, 1998; Weatherburn, Kumari & Clarkson, 1999).

There is always a danger in presenting an over-simplistic view of a labelled group. PLWHA have complex needs that are changing and highly individual. HIV is not confined to those from a particular class, ethnic group, educational background, sexual orientation or gender. For instance, the perception that HIV will remain largely confined to male homosexuals, has recently been questioned by figures which show that almost 50% of all individuals newly diagnosed in 1999 had acquired HIV heterosexually (PHLS, 2000). For all those diagnosed:

'To learn that you are living with a fatal disease is never easy. To learn that the disease carries with it some of the most negative social connotations ever known is particularly difficult.' (Aggleton, 1996).

Combination therapy

New diagnoses in the UK of HIV infected individuals remain at over 2,500 per year. However, the death rate from AIDS dropped dramatically by two-thirds between 1995 and 1999 (PHLS, 2000). This downward trend coincided with the introduction of combination therapies which appear to have been effective for some in curbing the onset of AIDS and in reducing or eliminating the symptoms associated with HIV. Those who choose to start combination therapy treatment are not undertaking an easy option. The strict regime of drug taking and diet places restrictions on those who undergo this form of treatment. Further, it is not a cure or suitable for all and changes in the combinations of drugs may be needed with the possibility of the appearance of more or less temporary unpleasant and debilitating side effects.

There is no single, distinctive experience arising from the use of combination therapy. PLWHA have diverse experiences and views of the future. However, many have benefited from greatly improved health, to the extent that they have sought guidance from HIV agencies concerning opportunities for learning, employment, training and volunteering. Others not on combination therapy or failing to gain from it were also reported as rethinking their future possibilities and did not see these solely in terms of decline

(Anderson *et al.*, 2000). Combination therapy has affected the views held by PLWHA about life.

The Positive Futures Initiative

In 1998, as a response to the changing needs of their service users, a partnership was formed between a number of HIV agencies in London. Their aim was to work collaboratively to 'enhance the quality of life of PLWHA by ensuring access to services in education, training, informal learning, volunteering and self development'. This was realised through the introduction and development of the 'Positive Futures Initiative' (PFI) scheme, which aimed to provide PLWHA with information, advice and guidance about opportunities both within the participating HIV agencies and provided by outside mainstream providers. It was envisaged that enquirers to any HIV agency within the Initiative would be signposted to appropriate opportunities in the scheme or referred to an adult guidance worker employed by the PFI.

The study

This study was undertaken for the Elton John Aids Foundation to evaluate the PFI from the viewpoints of service users. The study included exploring users' perceptions of how well their needs had been understood and met. Their views were sought at three points over a period of a year and the findings used by the PFI consortium team to inform the ongoing development of the Initiative. This paper concentrates on those findings concerned with approaches taken by participants to planning for the future and their views of support.

Semi-structured telephone interviews were conducted with 34 HIV positive volunteer participants, 12 were interviewed three times, 17 twice and 5 once. The participants, who were accessed through the PFI agencies, were keen to offer their views and experiences.¹

Reasons for accessing the PFI

Reasons for accessing this service varied both in clarity and certainty between participants. Most participants interviewed had wanted to make a positive move towards returning to work or learning. The motivations of those who were planning to return to work varied. These included an improvement in health, inadequate benefits, a need to be useful, a desire to lead a 'normal' life, concern about others' perceptions of PLWHA receiving combination therapy still relying on benefits and an inner compulsion to do a worthwhile job with new found energy.

Others were not looking as far as the possibility of working. They viewed the PFI scheme as providing the means to access opportunities that would enable them to overcome isolation and the stress associated with boredom, to keep 'on top of life', to get a better outlook on life and to become positive about oneself.

Uncertainty and step by step planning

'If you don't know where you're going, you'll probably end up somewhere else.' (Campbell, 1974).

Uncertainty about the desirability, feasibility and timing of a return to work ran as a theme through many accounts. Although some had formulated ideas about their medium- to long-term future, many of the participants in the study considered that they could only plan in small steps and in the short-term. As Anderson and Weatherburn (1998) identified, for some PLWHA illness constrains life to dealing with the day-to-day and the therapies demand an unremitting attention to daily existence. In this study, some did not want to make specific plans beyond attending a first guidance interview or a first course. They expressed uncertainty and a reluctance to look beyond the short-term future, as their priority was to avoid potential sources of stress

(including setting themselves goals that may not be achievable), which they feared might trigger a deterioration in health. Some also expressed uncertainty and concerns about benefits, housing and disclosure of HIV status, which they felt would influence their decision about seeking paid employment in the future.

Planning has remained a core component of career guidance, where clients' indecision and uncertainty have traditionally been seen as 'problematic'. Clients' unwillingness to look beyond a first step does not appear to lie comfortably with a guidance process where clients are encouraged to seek out information, explore options, develop career ideas and plan possible progression routes. Although a step by step approach in which individuals are reluctant to look beyond a first step may be interpreted as self-limiting and narrow, some participants felt that they had gained from the initial action they had taken. Although many were still unsure about their next step, by the third interview, most felt that participating in the Initiative had had a positive impact on them through having improved or acquired skills or gained in the personal/social aspects of their lives.

However, this did not apply to all. Some PLWHA appeared to have taken a course of action impulsively without planning, understanding, anticipating possible consequences or considering how to deal with these. Availability of an opportunity, together with the acceptance of a view that to be doing something was preferable to doing nothing, appeared to be a sufficient incentive for some to embark on a course of action. Taking 'chance' opportunities to re-engage with the future (e.g. taking an IT course for some appeared to be a chance event) may provide additional experiences, beyond the acquisition of new skills, for instance increasing self-confidence through socialising, becoming less isolated and experiencing encouragement and support from others. However, on reflection, some

¹ The reduction in numbers over the lifetime of the study was primarily due to participants moving, resulting in an inability for the researchers to renew contact, rather than an expressed desire to withdraw.

considered that the opportunities they had undertaken had been inappropriate for them. A few had withdrawn and not known how to re-engage with considering their future. We suggest that encouraging PLWHA to access opportunities on the basis that the action and experience can **necessarily** generate future goals or result in personal growth has limitations.

Mitchell, Levin & Krumboltz (1999) suggest that clients need to be encouraged to explore and approach new opportunities with an open mind, to ask questions and to experiment. They propose that clients can be assisted to develop skills of curiosity, persistence, flexibility, optimism and risk-taking in order to recognise, create and use chance events. Guidance, which takes into account the approach advocated by Mitchell *et al.* may enable PLWHA who express uncertainty to make proactive, rather than reactive first step decisions. A prerequisite for this to happen is a recognition of their uncertainty by those with whom they make their first contact in the PFI scheme and of a need for referral to guidance **beyond** the provision of information about specific courses on offer.

'If you always know where you're going, you may never end up somewhere else.' (Gelatt, 1989).

Krumboltz (1992) argues, in relation to all clients, that indecision about making definite long-term plans is actually more sensible than making firm commitments when the future is so uncertain. As Law (1996) observes, anticipating the consequences of actions taken is problematic. Learning to review, to make adjustments and changes in the light of experiences, altered priorities and new opportunities is likely to be central to planning in the future. Guidance practitioners working with PLWHA, who may see their future as uncertain along many dimensions, may help by encouraging them to recognise that being uncertain about the future is 'OK'. Setting goals need not be seen as a 'mill stone' or a potential source of defeat and stress if opportunities for review, adjustment and change are available. Discussing 'risk-taking' and possible strategies for 'risk-reduction' prior to a commitment to a possible course of action with those who lack self confidence may enable them to take positive first and subsequent steps forward.

PLWHA who contact the PFI scheme may also be experiencing the added complication of going through a process of re-adjusting to the idea of having a future at all. As Anderson & Weatherburn (1998) note, PLWHA who undergo combination therapy have varied and unique attitudes and approaches to considering the impact of those therapies on their future. Working with PLWHA clients from a basis of understanding how they view their present and to what extent they feel prepared to imagine, invent and plan for the future would appear to be central to any intervention which seeks to assist clients to move forward.

Initial support

Some PLWHA who participated in this study were concerned that their initial enthusiasm for becoming engaged in taking action towards the future needed to be recognised and addressed when they first approached the Positive Futures Initiative service. They were anxious to make a decision and take action while feeling well enough, before losing the initial impetus and, for some, the courage that it had taken for them to contact the service. The individual who is their first point of contact within a guidance service for PLWHA clients may need to consider with clients how they could be supported to maintain this enthusiasm if they are required to wait for access to guidance, a course or other opportunity.

Following an initial enquiry, a range of possible appropriate next steps could be offered. Optional activities which provide a means of continuing the initial contact made with the guidance provision may help to sustain interest and motivation. For instance, the study showed that some participants had felt nervous about having a discussion with a guidance worker and confused about their thoughts and what to say. Providing a pre-guidance proforma for them to complete may act as an aide memoire for them to refer to in a guidance interview and as a means for them to begin the process of clarifying their thoughts - a starting point from which to discuss their future. Others might value having access to information or to those who are attending course(s) and are willing to discuss it with them.

Continuing support

Of those who embarked on a course, a few had experienced periods of ill health between the first and second interviews with the researcher. Despite missing course sessions, they had felt supported by the tutor and/or their PFI contact and managed to continue. For some who withdrew, intervening and urgent life events (for example, moving accommodation or experiencing difficulties with benefits) left them feeling that they did not have the physical resources to deal with '... more than one thing at a time ...'. They felt that dropping out of a course and subsequently losing contact with the PFI scheme seemed to be the only option at the time.

Savickas (1997) proposes that practitioners need to help clients to develop into the person they want to be, rather than to view their future in terms of a 'linear continuum of developmental tasks'. This appears to be particularly relevant for some people living with HIV (PLWHIV) who are going through a process of re-evaluating their lives alongside which financial, personal and social

insecurity, together with uncertainty about their future health may present them with 'foreground' dilemmas of a more immediate nature. Participating in a new course of action, e.g. volunteering or undertaking a course may increase physical and psychological stresses, resulting in less energy and personal resources on which to draw to cope with other life stresses which may arise. If guidance practitioners are concerned with helping PLWHA clients to 'become', then this process could be facilitated by the provision of support mechanisms when issues arise.

Having access to support when needed would appear to be of particular importance for individuals who are taking a step by step approach to looking to the future. Although the need expressed for further support varied in both type and level between individuals, not all felt that they could always take the initiative to seek support and would have valued being followed-up. Some wanted to be offered an opportunity to refer back for further guidance about the next step they might take or how to change direction if an experience was not meeting their needs. A mechanism for follow-up agreed with individual clients would enable providers to initiate an offer of guidance at specific transition points which can be anticipated, e.g. when coming to the end of a course of action. Transition points which are not predictable, e.g. dropping out from a course or placement, might be anticipated as possible scenarios with clients and possible re-contact arrangements agreed.

A holistic approach

Career guidance practitioners who work with adults are well aware of the multiple dimensions and interconnected aspects of their clients' lives, which affect how they view their future plans. Proponents of a systems approach to helping (Egan *et al.*, 1979; Hansen, 2000) point to the importance of helpers recognising that what happens in one part of a client's life affects other parts. Some participants in our study found achieving a balance between maintaining their health, whilst engaging in additional, new activities as well as having sufficient energy to cope with day- to- day problems could be a delicate one.

In this study, the suggestion was made that a holistic approach to life planning could be usefully incorporated into the PFI scheme to assist PLWHA in exploring how they might accommodate and manage issues specifically related to living with HIV and when engaging in new activities. For instance, this might include opportunities to consider positive strategies for maintaining energy levels through managing stress, keeping fit and diet management. Part of effective guidance provision could include helping individuals to identify options and making choices about different lifestyles which could enable PLWHA to make positive moves towards taking control and managing their future.

Conclusions

The PFI scheme was a groundbreaking service requiring a re-orientation in HIV agency service user provision and the scheme has continued to develop. (It has recently been re-named Positive Futures, Positive Lives). Through their accounts the participants in this research have raised issues which have wider implications for guidance with PLWHA. Positive guidance to help PLWHA to face the future requires that practitioners are prepared to understand the uncertainties and concerns of this client group. Approaches from this study which appear to be particularly relevant are:

- providing opportunities to prepare for the initial guidance interview
- helping clients to work with strategies for planning with which they feel they can cope
- providing opportunities to access support from the first contact onwards
- agreeing the type and timing of follow-up and subsequent support initiated by the guidance provider.

Further, PLWHA who lack confidence may need help to consider risk-taking by having the opportunity to anticipate potential consequences before commitment to action and know that they can have access to support to deal with these. The complex and individual issues which PLWHA face would benefit from practitioners adopting a holistic approach rather than one which is narrowly focused on guidance into work, volunteering or learning if they are helped to face the future with confidence.

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