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<http://dx.doi.org/10.1177/0308022617698168>

Title	The development of a workbook to explore meaningful occupations after life-changing events
Authors	Taylor, J and Jones, V
Type	Article
URL	This version is available at: http://usir.salford.ac.uk/42353/
Published Date	2017

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Title: The development of a workbook to explore meaningful occupations after life changing events

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Research ethics

Ethical approval was awarded by a University of Salford Research Governance sub-committee (REP11/070)

Declaration of conflicting interests

The Authors declare that there is no conflict of interest.

Funding

This research received no specific grant support from any funding agency in the public, commercial or not-for-profit sectors.

Acknowledgements:

The Authors would like to thank the North West Cancer and Palliative Care Special Interest group and the Laryngectomy and Myeloma Support groups for their valuable contributions to this project and to the resulting 'What Now? Workbook.

The development of a workbook to explore meaningful occupations after life changing events.

Abstract

Introduction: Following serious illness or other traumatic event, individuals can experience a disruption of identity. This is related to an altered ability to engage in the routines, interactions and occupations of everyday life. The meaningfulness of occupations and of life itself can be changed or diminished. Because engagement in occupations contributes to identity construction, a practical tool to systematically explore the unique meanings of particular occupations to an individual could be of value in helping to re-establish a positive way forward. The aim of this study was to develop such a therapeutic tool, based on a framework of ‘the occupied self’.

Method: A participatory design approach was employed to engage the expertise of potential end-users of the tool: 6 occupational therapists in cancer services and 9 people living with cancer. The prototype ‘What Now’ workbook and associated guidance notes were incrementally developed over a period of 8 months.

Results: The workbook was judged by the expert advisers to be relevant, useful and user-friendly with the potential to benefit carers, retirees and those recovering from life-changing events and illness in a variety of ways.

Conclusion: The final version of the ‘What Now’ workbook is now ready to be tested in practice.

Keywords: Occupations, participatory design, therapeutic tool, identity, identity disruption, cancer.

Introduction and literature review

The lifelong process of engaging in occupations enables each person to construct a unique identity. This process of construction is based on the societal and personal meanings that occupations have (Christiansen and Townsend, 2004; Unruh, 2004). The theoretical relationship, grounded in a symbolic interactionist perspective, between identity and the activities in which we engage (Christiansen, 1999), is supported by a range of empirical work (e.g. Haggard and Williams, 1992; Hunter, 2008; Reynolds and Prior, 2003). Our occupations are powerful forces in the development of the self, by enabling the achievement of important goals and end-states and by allowing the expression of various dimensions of the self (Carlson et al, 2014). With our identities and through meaningful occupation we negotiate the world and show who we are.

A resilient and stable sense of identity is often taken for granted until disrupted by illness, acquired disability or other significant trauma. Following such events the individual can experience a loss of self (Charmaz, 1983) and the anticipated trajectory of the life is interrupted; Bury (1982) has called this biographical disruption. There is evidence of this disruption in a range of conditions such as cancer (Hughes, Closs, and Clark, 2009; Little et al, 2002; Hubbard, Kidd, and Kearney, 2010), acquired brain injury (Gelech and Desjardins, 2011), multiple sclerosis (Irvine et al 2009) and mental health problems (e.g. Carless and Douglas, 2008) where it can have significant detrimental impact on recovery and well-being. When identity is disrupted, a sense of continuity is threatened and contradictory and unstable views of the self might emerge. The individual may experience a sense of helplessness and find that their patterns of occupational engagement are changed (Carless and Douglas 2008; Gelech and Desjardins, 2011; Hughes, Closs, and Clark, 2009;

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Little et al, 2002; Hubbard, Kidd, and Kearney, 2010; Irvine et al, 2009). In the aftermath of such trauma the meaning of individual occupations and, indeed, the meaning of life can be altered. Occupations might be abandoned and the individual might feel unable to move forward positively with their life. If engagement in occupations is changed, then the process of identity construction is disrupted and well-being and recovery are jeopardized. The challenge for the individual and the occupational therapist is to find ways to re-engage with the meaningfulness of occupations and life itself.

In a recent study (Taylor and Kay, 2013), the narratives of members of the general public were analysed for their meanings in order to better understand how occupation contributes to the construction of identity. Based on systematic analysis of these meanings, a framework of the ‘occupied self’ was developed, providing a simple structure for understanding this concept (See Figure 1).

Figure 1. The Framework of the Occupied Self (from Taylor and Kay 2013, p 7)

				DIMENSIONS		
				The located self	The active self	The changing self
FACETS	Society and relationships		Agency			Self is changed
	Time		Competence			Occupation is changed
	Place		Morality			
	Body / mind					

The framework is organised around three dimensions, enabling the occupied self to be envisaged as located, active and changing. Each dimension has facets which may or may not be important for each individual in the construction of a unique identity. Most importantly, the framework does not just allow the analysis of an occupation: it allows the analysis of *what an occupation means* to a particular individual. For example, is Sally’s enjoyment of hill-walking about getting fit, becoming part of the countryside, or practising

her map-reading skills? Occupations may mean one or many things to an individual but these may not be identifiable until carefully analysed.

The framework enables a detailed and systematic understanding of the ways in which occupations contribute to identity and so has the potential to be developed into a practical tool for occupational therapists and their clients.

The aim of this study was to develop a therapeutic tool in the form of a workbook, based on the above framework, which is judged by potential end-users (i.e. therapists and people who have experienced traumatic illness or life events) to be relevant, user-friendly and useful.

Design

The study used a participatory design approach (Ellis and Kurniawan, 2000; Zaphiris and Constantinou, 2007) in which an end-product is designed with contributions from people considered to have relevant expertise and who might themselves be possible end-users.

This type of design is based on three premises: that it will aim to improve quality of life, that it is collaborative and co-operative, and that it is iterative, based on a cycle of interactive feedback and design development (Ellis and Kurniawan, 2000). The study was designed so that a potential therapeutic tool, a workbook, could be evolved to a point of satisfaction through collaboration between groups of expert advisers and the researchers.

The individuals recruited for this study were specialist occupational therapists and people who had experienced a traumatic illness; rather than being participants or research subjects, their role was to help in the design of the workbook and to act as '*specialist advisers, providing valuable knowledge and expertise based on their experience of a health condition or public health concern*' (INVOLVE and NRES, 2009, p1). In accordance with this

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guidance, ethical approval was not required through the NHS National Research Ethics Service; however ethical procedures were adopted, including gaining ethical approval from a university Research Governance sub-committee, to ensure best practice in relation to those who were volunteering their time and expertise.

Method

An approach used by Ellis and Kurniawan (2000) was employed to engage the advisers in the design process. This approach consisted of 6 steps:

1. Establish participation from people who would be possible end-users of the workbook
2. Develop a user model or a rough prototype
3. Present the raw idea to the users and map possibilities
4. Develop the prototype
5. Elicit and integrate feedback
6. Continue the iteration until a satisfactory design is achieved.

Because of the incremental and iterative nature of this process, each stage of working with the participatory design group after step 3 was dependent on what had gone before. Here the process is described with a ‘broad-brush’ approach, whilst the Results section will provide a more detailed account of the design development in steps 3 - 6.

***Step 1:** Establish participation from people who would be possible end-users of the workbook*

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Whilst it was not intended to design a workbook solely for people living with cancer, it was judged that they would act as good representatives of people whose identities might have been impacted on by the trauma of diagnosis, disease and treatments. A further group of potential end-users, occupational therapists working in cancer care and survivorship services, was also invited to be involved.

Presentations about the project were carried out to occupational therapists in a local Cancer and Palliative Care Special Interest Group and to two local non-NHS support groups for people living with cancer or its consequences, and who were no longer engaged in any active treatment. The presentations were the starting point for establishing participation by developing good working relationships (Ellis and Kurniawan, 2000). Although it was not the intention to recruit people with particular types of cancer as the expert advisers, support groups proved to be a convenient way to find people. Thus, a support group for people with laryngectomies and one for people living with myeloma were approached. Following the presentations, group members were invited to volunteer to become expert advisers to the project. Information sheets were provided that invited discussion about expectations and clarified the role of adviser. Written consent was gained and advice provided about retiring from the study at any point, if so desired.

The expert advisers:

In total, six occupational therapists from the special interest group, three people from the laryngectomy group and five from the myeloma group volunteered (see Table 2). Mutually convenient locations for meetings with the three groups were organized, refreshments provided and travel costs reimbursed. Two meetings, lasting up to 90 minutes, were carried out with each group at four-to-six week intervals. Meeting each group

separately was a means of ensuring that their different perspectives and unique experiences were captured.

Ethical considerations:

Acknowledging that some sensitive information, either personal or third party, might be shared in the meetings, the advisers were asked to consider this and respect confidentiality. Distress resulting from discussing sensitive and emotional issues was also a risk, but this was mitigated against by the nature of the special interest and support group membership. Also both researchers had relevant clinical backgrounds (mental health and palliative care) and personal experience of cancer services and, as such, had some empathic appreciation of the issues faced by therapists and service users dealing with the post treatment phase of cancer survivorship.

The recording and storage of personal data complied with standard research ethics procedures.

Step 2: Develop a user model or a rough prototype

Based on the theoretical framework described above (from Taylor and Kay, 2013) and prior to the first meeting, a draft prototype of the workbook (Version 1) was developed, featuring a series of sections, each populated by questions derived from the dimensions and facets shown in Figure 1. Personal testing of the workbook by the authors prompted some early changes such as using the word ‘activity’ instead of ‘occupation’ throughout the workbook, as it is more familiar to lay people.

Basic instructions for completing the workbook were included in the introduction. An attempt to make the workbook look attractive and accessible was also made. A list of questions was prepared to take to the first meetings, focusing on accessibility of wording,

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possibilities for development and on the ways in which the workbook could be administered.

Step 3: Present the raw idea to the users and map possibilities

The first meeting with each of the three groups began with an introduction, further discussion of the project and clarification of roles. The prototype workbook (Version 1) was presented and explained. The advisers were invited to examine it and to complete one or two sections before discussing:

1. The usefulness, usability and relevance of the prototype
2. Design problems
3. Suggestions for design and content
4. Potential usage of the workbook
5. Suggestions for workable solutions to the problems identified

Formal research data collection and analysis procedures were not appropriate as the focus was on the collaborative process of participatory design; however, the discussions were audio-recorded and field-notes made for reference in the development process. At the end of the meeting the advisers were invited to take workbooks home to trial them in their own time, in relation to a particular chosen occupation.

Step 4: Develop the prototype

The workbook was first presented to the occupational therapists to seek their advice in ensuring that the wording was appropriately sensitive. The discussions from the first meetings were used to guide the development of the workbook into a new version to take to subsequent meetings. Where a suggested improvement was not included, the rationale for

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this was explained to the advisers. Using this process four incrementally improved versions were produced over 8 months (Table 1).

Step 5: Elicit and integrate feedback

The revised workbook was taken to the second meeting with each group, so that the advisers could evaluate it. Further discussions centred on the advisers' experiences of completing a workbook. The five issues listed in Step 3 were revisited with audio-recording and field notes made, to aid memory for future revision.

Step 6: Continue the iteration

The development process continued over two meetings with each of the three groups (six meetings in all), the evolving workbook being taken to the next round of meetings in its latest version.

Table 1: Participatory design plan incorporating steps 1–6 above.

	Find and engage with expert advisers
↓	Develop a user model or a rough prototype (Version 1)
↓	Discuss with expert adviser occupational therapists (Meeting OT1)
↓	Develop the prototype based on feedback (Version 2)
↓	Discuss with expert adviser occupational therapists (Meeting OT2)
↓	Discuss with expert adviser laryngectomy support group (L) members (meeting L1).
↓	Discuss with expert adviser myeloma support group (M) members (meeting M1)
↓	Develop the prototype based on feedback (Version 3)
↓	Discuss with expert adviser laryngectomy support group (L) members (meeting L2)

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↓	Discuss with expert adviser myeloma support group (M) members (meeting M2)
↓	Develop the prototype based on feedback (Version 4)

Results of the design process

The six meetings with the expert advisers were fruitful, each meeting contributing to the sequential development of improved versions of the workbook.

Due to other commitments and illness, not all of the advisers could attend both of the relevant meetings. The number of expert advisers attending each meeting is shown in Table 2.

Table 2. Attendance and demographics of expert advisers at each meeting.

Expert advisers	Meeting	N	Gender mix
Occupational therapists	OT1	6	6 women
	OT2	5	5 women
Laryngectomy support group	L1	3	3 women
	L2	2	2 women
Myeloma support group	M1	4	2 women / 2 men
	M2	6	4 women / 2 men

The ways in which the six meetings contributed to the development of the workbook are organised below, around eight broad questions. Some of these questions were introduced into the meetings by the researchers, reflecting the aim of creating a workbook that would

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be usable and useful; some arose, however, from spontaneous points introduced by the advisers. The intention is for this results section to reflect the collaborative and participatory nature of the process. The sources for the issues raised are shown in brackets, using the abbreviation format shown in Table 1.

Question 1) How should the purpose of the workbook be introduced to the client?

Version 1 of the workbook had an unclear introductory section (OT1); it was suggested that this could be improved if basic occupation-theory based concepts were explained and if the user were helped to think of a range of personally meaningful occupations against the backdrop of their life to date; one occupation could then be selected as a focus for the rest of the workbook. These changes were made. This section was improved further to reflect two important remarks that were made in response to Version 2: firstly that adaptation to a life-changing event is a life-long task (L1) and that it is important to give information early to help adaptation. *'You can't have too much information too early, but you have to be very sensitive to the individual's needs'* (L1). Version 2 was also improved when the M1 group advised that the introduction needed to include an overview of the whole framework, to help guide the user through the rest of the workbook and establish its value.

Some frustration was expressed by one group (M1, M2), who felt that there was no indication of what filling in the workbook would lead to. Advice that the workbook should include an information-gathering and a follow-on stage resulted in an end section called 'What Now?' which asks the user to reflect back on their responses and consider what has been learned about the self, whether they better understand the meaning of this special occupation, and the implications for planning goals for the future.

2) How should the client be advised on how to fill in the workbook?

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The expert advisers each took a copy of the workbook away to try it out. This was Version 1 in the case of OT1 and Version 2 in the case of L1 and M1. This trial proved to be powerful in terms of capturing people's responses to the experience and the practical problems associated with completing it.

Some questions were found by some people to be personally irrelevant but they wondered if it was still important to attempt an answer (OT1, L1). It was important, for us, to ensure that the workbook retained flexibility and an ability to capture the uniqueness of the individual, so instructions were added throughout, advising the user to leave sections blank or answer with just one or several words, as desired.

It became clear that our quest to encourage people to focus on a single occupation was not simple. At the first attempt some of the advisers (L1) selected, for example, roles (e.g. 'being a grandmother') or broad clusters of occupations (e.g. 'going on holidays'), which made an exploration of meaningfulness difficult. Several iterations of the language and instructions were made to help the workbook-user focus on a personally meaningful and purposeful occupation; this was deemed essential for the workbook to be most effective. The guidance document for the occupational therapist¹ was also amended to direct the therapist to help the user focus on a specific occupation.

Some of the expert advisers (M1, L1) felt frustrated that we asked them to complete the workbook for only one activity and thus a suggestion was added in that the workbook could be used repeatedly, for other occupations, if desired.

3) How can the workbook be made attractive and accessible?

The groups provided useful advice about improving the language and presentation of the workbook, and this was reflected in the evolving versions; changes were made to address

¹ hereafter referred to as the Guidance Notes

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repetition, improve clarity, accessibility (OT1, L1,M2) and layout, e.g. the style of section headings (L1,M1).

The workbook is quite long and has several sections. Version 1 was thought to be a little daunting and tedious (OT1) and so clearer section breaks were inserted. Cartoon pictures were added for visual attractiveness, along with attractive, helpful and age-appropriate call-outs, (L1, M2), to give instructions and permissions throughout (e.g. “take a break now”). One of the most difficult problems identified by all of the groups was that the questions were written in the past tense, e.g. ‘Did the activity involve helping other people?’ Suppose, the groups asked, the client was being asked to talk about an occupation that they could no longer do? Would this be distressing? A neutral tense was suggested but grammatically this was not possible. In the end we continued to use the past tense, but added an instruction that encourages the user to focus on memories of experiences rather than the idea of loss.

4) What is the best way to administer the workbook?

Three debates emerged about how the workbook could be administered. One, introduced by the researchers, was whether or not it should be completed alongside a therapist or self-administered. All three groups decided that the workbook could be self-administered, but that this should be followed up quickly by discussion with an occupational therapist in case emotional support was needed. It was noted, however, that in some cases it would be better to have the therapist lead the client through the workbook by sitting alongside or by interviewing. There was agreement that flexibility to accommodate each client’s needs and abilities would be required. This led to a significant development of the Guidance Notes. These now (Version 4) encourage the therapist to use clinical reasoning to administer the workbook in the most appropriate way for each client. Some people would be happy to fill it in completely independently and control their own pace, but others might require more

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help, guidance and encouragement (M2). Some might complete the workbook in one sitting, whilst others may need to have it broken down into sections. Some might prefer a solitary approach, whilst some might prefer a conversation. It was clear that the workbook could accommodate a flexible, person-centred approach.

A second debate considered whether or not the workbook could be completed on-line, but it was decided (OT2, M2, L2) that it is too early in the workbook's development to think about this.

The third debate (OT2) was about whether, if a therapist is involved, this should *only* be an occupational therapist. This was agreed, given that the workbook is based on a deep and theoretical, as well as practical, understanding of occupation and its relationship to identity, health and well-being. There was concern that, in the absence of an occupational therapist, a superficial view of everyday activity might be taken. The Guidance Notes were amended to make this clear.

5) What guidance would the administering occupational therapist need?

The discussion around how the workbook should be completed had an impact on how the Guidance Notes evolved. Later versions included guidance that emphasized the important of the occupational therapist using clinical reasoning skills to know how best the workbook would serve their practice with a particular client. All three groups wanted flexibility and responsiveness to individual needs to be at the core of the workbook's use. The Guidance Notes final version now has four sections:

1. When is this workbook appropriate to use?
2. A tool for occupational therapists
3. How should it be used?
4. How are the results of the workbook used?

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6) Is the workbook useful? If so, in what circumstances?

The expert advisers were asked direct questions about the workbook's usefulness, but several unexpected comments were also made. These are outlined below.

Some general comments were made which seemed to confirm the potential power of the workbook. It was seen as a way of helping people to 'get back to basics' after a traumatic illness or event and find a way to start life again (L1). It was described as a process of 'learning to adapt to a new state of affairs' (L1). One adviser said that completing the workbook had 'made me understand how I got to where I am' (M2), whilst another said the workbook 'makes you think about who you are and where you are now' (L2). One member of the M2 group gave a useful summary: 'The potential value of the tool, as explained and understood by this group, is that it helps people to look at what makes activities (and life) meaningful. It helps to work out ways that very meaningful activities can be adapted now, and into the future, and also helps people to find new activities with similar meaning, that can serve the same purpose.' The workbook was felt to fill a gap in current resources (M2). The expert advisers suggested people that might benefit from use of the workbook, such as carers (M2), people who are retiring from work and people in palliative care services, as well as in legacy and life-story work, discharge planning and recovery work (OT2). The occupational therapy expert advisers were particularly pleased that the workbook helps to celebrate the importance of occupations and their meanings, and could help people to analyse their own activities (OT2).

7) Are there any disadvantages or risks associated with the Workbook?

Each group noted that the workbook, due to its focus on thinking about the past and possibly 'lost' occupations, might arouse feelings of sadness. Indeed several people talked

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about their own sadness and nostalgia when filling it in, but despite this, they reflected on how enjoyable and helpful the workbook was (OT2, L2, M2). All of the group members felt sadness was part of the process of recovery and adaptation and it should not therefore be viewed negatively. Where the workbook uncovered substantial sadness or difficulty, a referral to counselling might be appropriate (OT2).

8) What should it be called?

A consensus on the name of the workbook was not reached, but helpful discussions contributed to its development. The occupational therapists suggested we remove some ideas from the list, for example, ‘Getting to the core of you’ might be inappropriate where a client has an unseen tumour; ‘Building a healthy self’ might be inappropriate for use in palliative care. A list of options was taken from the initial meetings with the occupational therapists to the meetings with the support groups. The ‘What Now’ Workbook was chosen as the final name.

Discussion

The aim of the study was to develop, using a participatory design approach, a therapeutic tool based on the framework of ‘the occupied self’, which is judged by potential end-users to be relevant, user-friendly and useful. The results section above has described how potential end-users contributed to the development of the ‘What Now?’ Workbook, designed to help people who have undergone trauma and serious illness to understand the meaningfulness of certain occupations and to use this understanding to plan a positive way forward.

In addition to helping with the development of the workbook, the expert advisers provided substantial confirmation that it would be useful and highly relevant in their own experience.

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The members of the support groups in particular confirmed that their identities had changed due to their illness (and associated treatments) and recognized that they might have benefitted from some therapeutic input of this nature, although it should also be noted that some people said that they had, in effect, found their own way forward. The value of the workbook was recognised as its ability to facilitate an understanding of what had contributed to identity and in focusing attention on what was important and why, in relation to meaningful occupations. As suggested in the paper by Milbourn et al (2014), those who have experienced biographical disruption will benefit from a focus on the everyday experiences of their unique life world. The 'What Now' Workbook also requires the user to reflect on past experiences and identities through an exploration of a single occupation, and then to shift focus to what Blank et al (2015 p206) have called 'wanted future identities'.

The idea of exploring the meaningfulness of the things that we do was new to the support group members, but it was quickly assimilated and appreciated as a powerful concept in helping to bring about change, as has been proposed by Dubouloz (2014). It was also recognised that the introduction of a therapeutic tool such as this workbook needs to be done at the most appropriate time for the individual. The occupational therapists thought that it would be inappropriate in the acute phase of illness, but they argued its usefulness for those in recovery and survivorship, and also for those in palliative care services, who may wish to explore meaningfulness. The support group members were also clear that the point of intervention needed to be chosen with care and sensitivity. The occupational therapists stressed that an underpinning knowledge of occupation-centred theory was essential, and so the workbook should be administered under the supervision of an occupational therapist.

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There were some key issues in the development of the workbook, the first and most significant being the affirmation that the power of this therapeutic tool lies in its respect of the individual as a unique being. Although the format of the workbook is structured, the client is encouraged to approach its completion in a way with which they feel most comfortable: questions can be ignored, or answered with a short essay or one word. The purpose of the workbook is to enable a conversation with the self and the therapist about meaningfulness, identity and the future. The workbook is not about activity analysis, nor does it offer a standardised assessment; it is about an individualized approach to understanding personal meaning. Flexibility and the idiosyncratic nature of the human being are placed at the forefront. The ‘What Now’ Workbook helps the client and therapist to think about the client’s life in an occupation-centred way (College of Occupational Therapists, 2015).

It became clear during the participatory design that, whilst the workbook offers a series of questions exploring past experiences of meaningful occupations, a ‘what now?’ was needed to link these thoughts to the future and a positive way forward. The workbook enables a link to be made between the past life story populated by occupations, and the shaping of a new future. A traumatic life event such as cancer can result in an individual feeling that they have fewer occupational choices. Nayar and Stanley (2015) have suggested that occupational adaptation, being associated with identity and well-being, might be a way for people to consciously develop new occupational choices for the future. The ‘What Now?’ Workbook could be a tool to facilitate this process.

A further issue that emerged was the importance of clear guidance notes for the occupational therapist on using the workbook alongside their clinical reasoning skills, to determine with whom to use it, when and how. The workbook encourages a focus on the

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uniqueness of the client and the uniqueness of their relationship with a particular occupation. It also encourages the therapist and client to explore emotions such as sadness, frustration and joy in relation to occupations, in order to facilitate moving forward. It is not uncommon to experience emotional responses to changes in occupational engagement (Williams and Murray, 2013).

Overall, the use of a participatory design approach proved to be successful in that it helped to ensure that the workbook was accessible and relevant and to give it credibility. Also, during the initial design of Version 1 over-exposure had blinded us to potential strengths and weaknesses. The expert advisers often saw the obvious, or, conversely, raised issues that we hadn't anticipated.

The number of advisers was small and this had its advantages and disadvantages. Because we used three very specific groups of expert advisers it could be argued that they did not represent other people who might be potential end-users of the workbook. A theoretical relationship can, however, be said to exist between these potential end-users and others who have been through, or worked with, life changing trauma and the disruption of identity.

The expert advisers affirmed the value of applying the underlying theory in relation to real disrupted lives and occupational therapy practice. The participatory design process used here shaped a potentially useful workbook which is ready to be tested in practice.

Conclusion

This paper has described how three groups of expert advisers contributed, in a participatory way, to the evolving design of a workbook which may have therapeutic value within occupational therapy in a wide range of settings. Specifically the workbook has the

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potential to enable a person to examine what makes, or made, a particular occupation meaningful for them, and to consider, with an occupational therapist's guidance, how that knowledge might help them plan a positive way forward. In this way the individual can preserve or rebuild identity after it has been disrupted and it is through their identities that people can have continuity, adaptability, resilience and the ability to participate.

Key Findings

- The workbook can help clients understand how their identity is linked to meaningful occupations, thus enabling positive future planning
- Flexibility, timing and support from occupational therapists are important factors.

What the study has added

- A participatory design approach ensured accessibility, relevance and credibility of a new therapeutic tool that has potential application across a range of settings for those who have experienced identity disruption.

Research ethics

Ethical approval was awarded by a University of Salford Research Governance sub-committee (REP11/070)

Declaration of conflicting interests

The Authors declare that there is no conflict of interest'.

Funding

This research received no specific grant support from any funding agency in the public, commercial or not-for-profit sectors.

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