



Section One: Literature Review

**The psychological experiences of people living with a heart transplant: A metasynthesis**

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<sup>i</sup> See Appendix 1-A for 'Author Guidelines'

## **Abstract**

### **Background**

Heart transplantation is a well-established treatment for end-stage heart failure. Despite its success at prolonging life, recipients often experience persistent psychological difficulties. However, little is understood about how to help this population.

### **Aims**

A metasynthesis of qualitative research into the psychological experiences of heart transplant-recipients was conducted to assess the current state of knowledge regarding this phenomenon, to identify avenues for psychotherapeutic intervention, and to inform theory.

### **Methods**

A systematic literature search of the databases PsycINFO, MEDLINE, Academic Search Complete, CINAHL and Web of Science identified 19 papers. Noblit and Hare's [1] approach to meta-ethnography was employed to synthesise their findings.

### **Results**

The synthesis yielded four themes: 'The ambiguous presence of the donor'; 'Reborn but still not in control'; 'Striving for autonomy and normality'; and 'The search for acceptance and new meaning'.

### **Conclusion**

The synthesis achieved its stated objectives by integrating and making accessible the disparate findings and by yielding novel insights. The most significant of these was that psychological recovery from heart transplants may mean not only accepting a range of losses and ongoing difficulties, but may also necessitate changes consonant with posttraumatic growth, such as finding new meaning in life.

**Keywords:** *Heart transplant, Psychological difficulties, Posttraumatic growth, Metasynthesis*

### **Introduction**

Heart transplantation (HT) is a well-established surgical intervention for the treatment of end-stage heart failure [2]. Despite its success at prolonging life, recipients often experience persistent psychological difficulties following the procedure. A review of salient research concluded that although distress typically reduces soon after the operation, 20% of recipients may meet the diagnostic criteria for Major Depressive Disorder within the first 18 months, while 21% may experience an anxiety disorder within the first three years [3]. Furthermore, a prospective investigation of recipients' quality of life [4] found that 21% experienced clinically significant distress throughout the first four years posttransplant, while psychological disorders have been found to become increasingly prevalent over the first five

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years [5]. Not only are these difficulties problematic in their own right, but there is evidence that they predict mortality [6].

Quantitative research has delineated variables that predict posttransplant psychological difficulties. Spending too little time on the waiting-list [4] and experiencing compromised physical functioning, neurological symptoms and lower recreational functioning [8] are predictive transplant- and health-related factors (although lower recreational functioning may also be consequential to psychological difficulties).

In terms of factors relating to individuals, past psychiatric history and female gender [4], poor social/emotional support, younger age and uncertainty about health [7], low hopefulness [8], low self-esteem and avoidant/passive coping strategies [9], and Type-D personality (denoting a dual disposition to negative affect and emotional inhibition) [10] are predictive. Posttransplant psychological difficulties have also been associated with low perceived control [11].

These findings theoretically enable services to screen HT-patients for the various factors so they may provide targeted support, to increase patients' perceived control over their treatment, and to develop psychotherapeutic interventions that increase their social support and active coping strategies, including the ability to effectively express their emotions. However, the degree to which this happens is unclear and very few studies appear to have measured the effectiveness of interventions designed to alleviate posttransplant psychological difficulties [12] [13].

Part of the reason for this deficit may be that relatively little is understood about the experiences of living with a heart transplant. Though useful, quantitative research does not always readily translate into guidance on how to address psychological difficulties. This is

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because it inhibits the identification and exploration of the meanings that people make of their experience and which account for ongoing distress and despair. Conversely, qualitative research is able to capture a more comprehensive, nuanced and authentic rendering of the phenomena it investigates.

Although a number of studies incorporating qualitative methodologies have been conducted into HT-recipients' posttransplant experiences, they address disparate aspects of these and have been undertaken in diverse contexts. Their application is therefore limited in two ways: firstly, their findings are scattered across numerous papers, presenting challenges to clinicians in terms of obtaining, reading and making sense of them as a whole; and, secondly, because they have been conducted on small samples and in specific contexts, their generaliseability is circumscribed. Integrating these findings would make them not only more accessible but also enable novel conclusions to be reached and greater generaliseability achieved [14]. Until relatively recently, however, there was no widely recognised means of integrating such findings in the way that systematic reviews integrate those from quantitative research. Metasynthesis [1] [14] has emerged to become arguably the pre-eminent solution to this problem.

Thus, the aim of the present review was to synthesise the findings from studies that utilise qualitative methods to capture HT-recipients' posttransplant psychological experiences. In so doing, a comprehensive account of these may be rendered so that psychological theory and psychotherapeutic interventions for this population might be developed.

## Method

### Search Strategy

An exhaustive list of potential papers was compiled from several online research databases between October 2013 and March 2014. The databases were: PsycINFO, MEDLINE, Academic Search Complete, CINAHL and Web of Science. These were selected because the degree of overlap and distinctiveness between them increased the probability that all the relevant papers would be identified (see Table 1 for the databases' characteristics).

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A comprehensive list of search terms pertaining to qualitative research was generated by utilising the thesauruses of the search engines that featured this functionality. These were inputted into the databases along with the term 'heart transplant\*'. Most databases featured filters that enabled more nuanced searching. The degree to which these were utilised was decided by reflecting on each database's focus. For example, PsycINFO publishes research specific to psychology, therefore applying filters risked screening out relevant papers; however, as MEDLINE is focused on the healthcare field in general, it felt appropriate to apply filters in order to limit what would otherwise have been a prohibitively large volume of papers. See Table 2 for a complete list of search terms and limiters.

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Searches yielded 1460 potentially relevant papers (including duplications). The following inclusion criteria were applied: a) only papers written in English; b) only papers published in a peer-reviewed journal; c) only studies incorporating qualitative methods; d) only papers capturing psychological experiences of the postoperative phase of receiving a

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heart transplant (e.g. papers that focused exclusively on the waiting-list phase were excluded); e) only papers capturing adults' experiences, or which delineated those of children (in recognition of fundamental differences in the life-stages between adults and children); and f) only papers whose findings are evidenced by quotations. Papers were excluded if they espoused an epistemological position that prevented their synthesis with papers from the epistemological position(s) adopted by the majority of the other papers.

The reference sections of the 19 remaining papers were checked for others. None were identified. Figure 1 depicts the search strategy.

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### **Quality Appraisal**

Each paper's quality was appraised with the Critical Appraisal Skills Programme (CASP) [15], a tool specifically developed to evaluate qualitative research. It appraises papers' sampling, data collection and reflexivity, their ethical and analytical rigour, and the clarity and value of their findings. The papers were awarded a mark of 0-2 for each of its ten questions: 0 meant that particular guidance was not met, 1 meant the guidance was partially met, and 2 meant the guidance was fully met. The papers received total scores of between 10 and 20 out of 20, with a mean of 16 (see Table 3 for a summary).

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Although quality appraisals are often performed to enable the exclusion of papers, all 19 were included in the synthesis. This decision was partly pragmatic: the papers were actually derived from 13 studies and the amount of relevant material they contained was often limited. Furthermore, Booth [16] argued that excluding studies because of

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methodological flaws could mean that important findings are overlooked. Therefore, the data from all the papers was felt to be not only valid but also necessary to produce the most comprehensive and useful synthesis possible.

As each paper derived from the same study had a slightly different focus, and therefore made different arguments and presented different supporting quotations, it seemed appropriate to include them all. Interestingly, papers derived from the same studies sometimes varied dramatically in their CASP scores, highlighting the inappropriateness of using such measures to exclude papers from reviews. Thus, the quality appraisal was primarily used to contextualise the papers' findings so that readers could make informed decisions about their validity. It is perhaps noteworthy that none of the meta-themes were heavily reliant on the lower-scoring papers.

A typology approach was utilised to measure, on a sliding scale, the depth of interpretation each paper attempted [17] (see Table 4 for a summary of the salient characteristics of each paper). The most superficial analysis was performed by the purely deductive paper [18], which applied a pre-existing model to its data. The mid-level of analysis was performed by the ten descriptive papers [19] [20] [21] [22] [23] [24] [25] [26] [27] [28], which provided conceptual or thematic descriptions of their data. The deepest level of analysis was performed by the eight explanatory studies [29] [30] [31] [32] [33] [34] [35] [36], which sought to interpret their findings.

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### **Characteristics of the selected studies**

Each paper was appraised in terms of its aims, epistemology, country of origin, participants' characteristics, methodology, analysis and key findings (see Table 4). Again, this helps readers contextualise the review's findings. Although rarely explicitly expressed, it was possible to discern papers' epistemological position from how they were written. They all adopted a critical-realist perspective, which holds that language reveals users' thoughts, feelings and experiences.

The studies were conducted in seven countries: the UK [29] [30] [34], USA [22] [23] [23], Canada [35] [36] [27] [26], Sweden [24] [28], Israel [35], Austria [19] [20] [21] and Brazil [31] [32] [33]. Sample sizes varied between three and 47 HT-recipients. All data were collected via semistructured interviews. These were carried out individually, with the exception of one study [36], which interviewed separate families.

Reflecting the preponderance of male HT-recipients generally [37], most participants were male; one study [23] addressed this imbalance by focusing exclusively on women. The length of time between transplant and interview varied between three months and 13 years. Several studies included additional populations. These were: kidney-transplant patients [24]; cardiac patients fitted with a Ventricular Assist Device (which replaces the functioning of a failing heart) or who had had one explanted [34]; HT-recipients' family-members [36]; and people diagnosed with panic- and tic-disorder [35]. In these instances, only findings applicable to the HT-recipients specifically or to all studied populations contributed to the synthesis. Only quotations from HT-recipients were used to evidence the meta-themes. Some studies included a small proportion of minors [19] [21] [28] [31] [32]. Findings and quotations attributed to them were excluded from the synthesis.

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Five papers did not specify which analytic approach was used (although each appeared to be a form of thematic analysis) [18] [21] [23] [24] [25], three utilised qualitative content analysis [20] [23] [28], five grounded theory [22] [29] [30] [34] [36], four phenomenological thematic analysis [31] [32] [33] [35], and two utilised an audio/visual methodology [26] [27]. A variety of designs were employed, including purely qualitative, mixed-methods, and others that utilised predominantly quantitative methods with qualitative elements.

Although the validity of integrating findings from studies with heterogeneous methodologies has been the source of debate [38], it was deemed appropriate to include such studies in the present metasynthesis. While this was again partly due to the limited pool of studies, it has been argued that synthesising research with diverse methodologies can yield findings that have more depth and which therefore offer greater utility [39]. An effective way to integrate studies with differing methodologies is to adopt a constructivist approach [40]; Zimmer [41] holds that each paper in a metasynthesis is equivalent to a separate voice in a qualitative study, each having its own social context and personal history that make it simultaneously unique but neither more nor less valid than the others. This perspective was invoked for the metasynthesis.

### **Analysis and Synthesis of the Selected Studies**

Noblit and Hare's [1] meta-ethnography approach (see Table 5) was channelled to facilitate the synthesis. Thus, the papers were read several times, enabling the reviewer to become conversant with their data. Initial notes were taken during each reading, then a list of key concepts pertaining to each paper was created. These were compared with each other to

highlight similarities and differences. Next, the studies were translated into each other and their findings synthesised by clustering similar key concepts together in a way that the final iteration accommodated the greatest number of them. These clusters went through several permutations before the final configuration of four meta-themes was determined (Table 6 depicts the construction of a meta-theme. Table 7 shows how the key concepts derived across the papers contributed to each theme).

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### **Synthesis**

Four meta-themes ('themes' henceforth) were identified. These were: 'The ambiguous presence of the donor'; 'Reborn but still not in control'; 'Striving for autonomy and normality'; and 'The search for acceptance and new meaning'. Table 8 shows which papers contributed to each theme.

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#### **Theme 1: The ambiguous presence of the donor**

Ten studies and 16 papers contributed to this theme, which encompasses the psychological effects of losing one's heart and gaining that of a deceased other. After the transplant, although patients initially felt euphoric relief [24] [25] [30] and incredulity at the operation's success [28] [32] some soon experienced durable grief for the hearts they had lost [30] [31]:

And then I had a big problem [...] I started to grieve for my own heart. [...] I got really worried about what had happened to my heart; what have they done with it? You

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know? My heart was important to me for forty-odd years and suddenly it's away. My mum and dad gave me my heart and I've gave it away; what happened to it? Then I felt pretty depressed. [30] (p.619).

Conversely, some reported few difficulties psychologically accepting the donor-heart as their own, particularly as time elapsed and fewer medical complications emerged [20] [24] [31]: "This is the strange thing about it, it feels as if it were mine, as if nothing organic had happened" ([20] p.1153). However, not all experienced the new heart so positively and this picture of unilateral acceptance was often complicated by distress not just from having a foreign body inside them, but the heart of a deceased person [20] [22] [23] [25] [26] [30] [31] [32] [34]:

I find it quite a spooky thought having a young man's heart inside...It's just learning to live with the thought that you've got something inside you that doesn't belong to you. I can't feel it physically, it's just psychologically, in fact it is not your own heart. ([34] p.35).

Some sought psychological help with this distress: "Today I live with the heart of someone who died...I had to see a shrink to accept that" ([32] p.222).

Others denied any emotional reaction to receiving the heart; this was interpreted as a defensive strategy protecting patients from further distress [20] [24] [29] [30], a hypothesis directly confirmed by some participants:

Then I tell myself that it really is of no interest to me, because I don't really want to know it. One just doesn't know what would be at the end of that. Surely one question then leads to another and then...No, it's better not to know anything. ([20] p.1153).

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Having sometimes been encouraged to depersonalise the donor-heart by medical professionals [24], recipients employed this strategy to help distance themselves from the fact of the donor's death:

I know that he was 16 years of age, came from Upper Austria, and was killed in an accident. That's all. I do not think about him at all. It is absurd... Well, let's assume you wear glasses and you don't need them anymore. They fit me, and you are willing to give them to me. What sort of feeling should I have towards you and your glasses? And just as I wipe your glasses as if they are mine, I supply the heart with blood. I would say I'm not thankful to the donor but to the surgeons. ([20] p.1152).

As avoidance of thoughts and feelings about donors became less prevalent over time [28], patients acknowledged these at various stages of the postoperative period [20] [22] [24] [25] [28] [29] [30] [36]. They expressed feelings of regret, grief and guilt about the loss of life:

I couldn't come to terms with that very easy, the thought of getting somebody else's heart. I used to lose sleep at night because I was thinking there was a healthy person somewhere that had an accident and gave you a heart, and that used to make me lose a lot of sleep. ([30] p.618).

Such feelings were sometimes compounded by patients' acknowledgement that in wishing for a heart prior to their transplant, they had implicitly been hoping for someone to die [21] [24]. This engendered feelings of culpability for the donor's death and fears of retribution in the form of organ rejection [24]. Guilt-feelings were further compounded if patients felt unworthy of the transplant [24].

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Gratitude to the donor and donors' families was frequently expressed [20] [22] [24] [26] [30] [33] [36]: "I was very grateful; I'll be indebted all my life to the chap that gave it to me" ([30] p.618). Again, this sometimes increased over time [24]. However, some were concerned the burden of gratitude risked turning them into a "living monument of the donor" ([25] p.168). Patients were sometimes unsure how to express their gratitude [20]. Those with religious inclinations performed rituals in donors' honour [20] [24] [36]. Others yearned to know more about their donor to feel a sense of connection to them [20]. Some wrote to the donor's family, when possible [26], or wished they could meet them [20] [22]. However, some felt that such contact might cause difficulties both for them and for the families concerned [22] [24]:

I think the worst thing would be reminding them of something that hurts. You don't know how people are going to be handling something. It's been two years, but how they're handling it now. Am I going to open up a new wound or am I just going to give them some joy to know that I'm still going and still doing pretty good? ([22] p.95).

Despite this desire to contact donors' families, the requirement imposed on some to write letters to them was a source of significant distress: "(It) was a little more painful, simply in that...because I got to learn about this person...although they were realistic before, but all of a sudden they have a family...it changes things" ([26] p.621).

Finally, some patients described postoperative transformations attributable to the donor-heart. While some ridiculed the notion that donor-hearts may have directly influenced their personalities ("this pile of flesh?" [19, p.253]), instead ascribing any postoperative personality changes to the effects of aging [29] or their traumatic transplant-related

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experiences [20], others expressed beliefs and fantasies about possible influences on their personalities of having someone else's heart [19] [20] [22] [24] [25] [30] [31] [33]:

Yes, I have changed. I want to avoid any kind of stress, if possible, and I have become much calmer [...] The new heart has changed me. One could say, well, not exactly, but one might put it like that: the person whose heart I got was a calm person, not hectic, and his feelings have been passed on to me now. ([19] p.253).

Whilst these beliefs mainly related to benign changes, some patients expressed concerns that the donor-hearts could influence them in ways they would experience negatively. Men sometimes communicated their difficulty accepting their female-donor hearts [24] [33], ostensibly because they believed that "men are stronger" ([24] p.396), while women also sometimes expressed a wish for a same-sex donor [24]. Furthermore, some patients reportedly attempted to adopt donors' hypothesised way of being in order to protect them from the risk of organ rejection [24]. Others purposefully sought to identify with the donor, asserting that the donor was alive in them [20] [24], possibly as a means of expressing their guilt or gratitude: "I think about learning how to ride a motorcycle. Now he has turned 19, he is allowed to. I'll teach him that, too" ([20] p.1153).

Overall, this theme concerned the challenges patients faced with mourning the loss of their own hearts and accommodating those of deceased persons. Although some patients appeared to be largely unaffected by this, there was evidence that this may sometimes have been a defence against further distress. Guilt about and gratitude to the donor and the donors' families emerged over time. Finding ways to manage and meaningfully express these feelings presented a challenge. Finally, the theme showed how some patients felt the donor-heart influenced their personalities, often in a benignly positive way, but sometimes

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anxieties about this potential influence reflected prejudices patients held, uncertainties about themselves, and fears of organ rejection.

### **Theme 2: Reborn but still not in control.**

Eleven studies and 14 papers contributed to this theme, which describes how the possibilities promised by patients' 'rebirth' were often obstructed by the suffering they continued to experience due to their ongoing loss of control over their health, treatment, self-motivation, independence, finances, and their emotions. It also describes how patients reduced uncertainty about their health.

Patients identified their heart transplants as a rebirth [25] [33]: "When I awoke from that surgery, it was as if you realise what it is to be reborn. It is as if you are free from all those problems, you will restart all again" ([31] p.319). However, their health remained fragile: "My health is not completely stable...I feel good sometimes, then it gets knocked back down." ([36] p.13). Unexpected by some, this was described as falling "from Heaven to Hell" ([21] p.310) after their initial joy at surviving the transplant process. Far from being able to simply relax and enjoy renewed health, "there are difficulties and I need to be careful" ([35] p.281).

The general postoperative discomfort patients experienced was exacerbated by fears of organ rejection [18] [23] [28] [31] [33] [36]. These fears sometimes increased with time:

Rejection: Just the word scares me that I'll die before I do all the things I want to do yet. Having to go through an annual admission every year, I hate those three days and wondering what the results will be. I feel more anxious and worried about rejection and serious side effects of the medications as I get farther from the transplant...sort of wondering how long can my luck hold?" ([18] p.4).

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Thus patients were left in a state of ongoing uncertainty about their health: "It seems that you are expecting that something is going to happen, and then you feel it won't happen, you know...Then it seems that you live on a tight rope" ([32] p.222). These fears were exacerbated by other HT-recipients' deaths: "Five of us were transplanted successively. Three of us are dead. And now I am in hospital...Who will be the next one to go?" ([21] p.310). Periodic bouts of infection and rejection necessitated further hospitalisation and more operations, heightening anxieties further [23] [31]. Distress was further increased by the vagueness of the symptoms they had been advised to remain vigilant for and the postoperative numbness that masked them [28], and by the monitoring process itself [24].

However, possibly because of the uncertainty and trauma associated with the various transplant phases, some patients wanted to reduce uncertainty by requesting that medical professionals withhold information about potential posttransplant complications and only provide words of encouragement:

Well, you have to encourage this person...never tell them...'Oh, my God, you know, tomorrow you are going to be worse', never say that to the person who went through a nightmare...never discourage people. ([27] p.4).

Similarly, some avoided other transplant patients: "I personally do not like having any contact with them because they would moan and they had different aches and pains, the things that I've got to go through, and sometimes I think its better not knowing what lies ahead" ([29] p.932).

Although cardiac medication ameliorated patients' concerns to some extent ("so far the medications seem to be doing their job" [18, p.5]), it not only left them subject to a host of worrying side effects [23] [36], but the demanding healthcare regimens they were expected to

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follow for the rest of their lives also reduced their sense of autonomy [18] [28] [31] [32] [33] [34] [35]. Furthermore, despite feeling grateful to the medical professionals who supported them throughout their transplant experiences and beyond [24] [28] [31] [32] [36], the perceived lack of clarity over various aspects of their regimens was a further source of uncertainty and consternation for some [28], while compliance was sometimes affected by self-control:

Laziness and lack of motivation are my problem. I know I should be exercising but I just can't get myself going. Also it's hard to exercise alone. It would be easier if I had someone to do it with or a class, but that's too expensive. I just can't afford it. ([18] p.5).

Although patients were grateful for their families' support [25] [29], aware of the impact of their illnesses and transplants on them [25] [29] [34], and sometimes resentful if family-members attempted to assume their normal routines too quickly [34], patients struggled with the lack of autonomy they experienced within their families. This was either due to overprotection from those who had become their carers [21] [25] [34] or because patients' children were fearful of leaving them [28].

Patients also experienced a lack of control over their finances. They bore additional costs as a result of their prescription-heavy postoperative regimens and ongoing sick leave [28]: "[The transplant] improved my heart and health, but caused lots of financial problems" ([18] p.4). Some also had to cope with the typical difficulties associated with aging, like arthritis and memory problems [18].

The sum impact of these difficulties not only left patients' emotions in a state of flux [23] [25] [34], but the constant uncertainty heightened doubts about their future wellbeing

[34]. Thus, although the transplant "improved the physical side of things [...] emotionally there's more anxiety, wondering if I will stay healthy, fear of rejection, future very uncertain" ([18] p.4).

Overall, this theme demonstrated that the sense of posttransplant rebirth patients experienced was complicated by uncertainty about their ongoing situations and continuing lack of control over their lives.

### **Theme 3: Striving for autonomy and normality.**

Nine studies and 11 papers contributed to this theme, which highlights how HT-recipients attempted to reassert control over their lives and to establish a sense of normality. In the midst of the postoperative tumult, gaining a sense of control over any aspect of their lives was of particular importance [34]. While the first step was the gradual reclamation of basic skills like breathing, walking and speaking [32], for some developing their autonomy further meant proactively assuming responsibility for their health: "One needs to take responsibility for his or her health and that begins with understanding what is expected of you in terms of medications, diet, and exercise" ([23] p.255). Developing a routine, one that accommodated the complexities of their medical regimens, helped to increase patients' autonomy and sense of normality [34].

For others, controlling the emotional impact of their ordeal was central. Patients sought to deny this to themselves and others [23] and avoided stimuli that might provoke difficult feelings, particularly in the immediate aftermath of the transplant:

I found I didn't want to see anything hurtful. I couldn't read the paper, you know, the Bosnia situation...I didn't want to think about it too deeply. I didn't want to hear anything nasty that there were children being abducted, raped, and all these things. I

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didn't want to know about it. It was almost as if I was an open wound and it would hurt too much [...] It was enough just to be coping with my situation. ([29] p.932).

Patients strove for a sense of normality by comparing themselves favourably with others, with their pre-transplant selves, or with worse scenarios that might otherwise have occurred [29] [34]:

I definitely put a hell of a strain on the family but I don't think it would be as much strain on the family as if I had snuffed it. I think that would have been a bigger strain, if I died without this transplant. ([29] p.933).

Although initially daunting [21] and subject to the vagaries of their medical regimens [29], socialising with friends and family was evidence of their emerging autonomy and sense of normality [25] [28] [29] [34]. However, this was sometimes problematised by the reactions of others: "For my neighbours I have become a mixture of miracle and zombie" ([21] p.311). Despite such challenges, patients keenly felt it when social resources were absent: "I lost a lot of friends and that's hurts me quite a bit. [...] I don't go out socially, I stay in. I don't have any social life" ([29] p.933).

Finally, autonomy and normality were conferred by patients' resumption of former roles, particularly those within the home and in employment [25] [28] [31] [33] [36]: "Many people at that time said: 'You can retire because you transplanted.' But I did not want to, I continued working. I work until today." ([31] p.319). However, this was restricted in the home by family-members' continuing overprotectiveness [34] or their unwillingness to accommodate patients' development:

I couldn't do a lot before I got my heart. He carried the load for me, the house and everything. And taking over the bills, and I just couldn't handle the stress of anything

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anymore. So he took over, and he did such a good job, now he doesn't want to give it back. ([22] p.95).

While some patients continued to perceive themselves as sick and did not attempt to return to work [25], those who did sometimes experienced workplace discrimination [25]: “You can’t get a job anymore. You quit a job, and you can’t find another. This is the bad part” ([33] p.590). Furthermore, patients sometimes found it difficult to communicate to employers just how susceptible they now were to infections [28]. Thus patients called for increased understanding of chronic illness within their wider communities [28].

Overall, this theme concerned patients’ efforts to re-establish their autonomy and to develop a sense of normality. It also described the challenges they faced in the pursuit of these goals.

### **Theme 4: The search for acceptance and new meaning**

Ten studies and 12 papers contributed to the final theme, which concerned recipients’ (eventual) acceptance of their situations and the utility of finding new meaning in life. Reaching a state of acceptance enabled them to manage their ongoing uncertainty and the challenges of their treatment regimens [22] [23] [28] [29] [34]:

You take these things [symptoms] as they come and accept them, and just get on with life because you're still living, and I've got grandchildren along the road that I would never have seen if I didn't have my transplant. ([29] p.931-932).

While time seemed to be a significant factor in reaching this point, adopting a positive attitude and harnessing their personal qualities enabled patients to more easily accept their circumstances and make the most of them [27] [29] [35] [34]: “You must remain positive,

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because if you give up it's deadly. You need to be positive. You need to believe you will get where you want" ([35] p.284).

Attempting to rediscover meaning in life and to attain self-fulfilment was an approach advocated by patients [23] [25] [28] [29] [31] [36]. This meant finding ways to be true to themselves, sometimes for the first time: "For once in my life it's me who decides" ([35] p.284). It also meant setting new goals:

It's a question of, you know, really setting yourself targets and goals all the time and being able to try to achieve them. I know one transplant patient in particular who went home and just sat himself down in an armchair and just let himself go. For me it's a complete waste of a transplant because he is not doing anything with his life. He should be out enjoying himself but he sits there and almost vegetates, which is sad. ([29] p.932).

Furthermore, it meant realigning their expectations of themselves and adopting a new outlook [25] [29] [36]:

Sure, [my family] did not always have the health we wanted or the money we needed, but we didn't let that affect us...You just learn to accept what you can do and make adjustments for what you cannot do...I'm just happy to be alive...there are so many things that you are able to do and to experience when you have more life. ([23] p.255).

While this new outlook allowed them to appreciate their families in new ways [25] [30] [34], to deprioritise money's importance [29], and to live more in the present moment than they might have done previously [28], it also meant acknowledging and accepting the losses they had incurred: "I had a very successful business, I was doing very well and had planned

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my future with it, and suddenly...it's cut away! It does affect you a little bit, and then you move on” ([34] p.34). This sometimes meant making very painful choices:

I asked Dr Y if I could have children. He said I could, but...I don't think so, because pregnant women must not take strong drugs, because it affects the baby, it is fragile, so I already know that I will not be able to get pregnant. ([32] p.223).

Patients also attempted to find meaning in the ongoing difficulties caused by their transplant experiences:

There must be a reason. There's a reason for everything in this world. I firmly believe that there's a reason why I've gone through what I've done and come out at this end. There must be a reason and maybe eventually it will be unfolded to me. ([29] p.933).

Sometimes the meaning they identified reflected negative self-beliefs they held: “I'm paying the price of being a bad boy all my years” ([29] p.933). Further to this, those with spiritual and religious inclinations drew on these as sources of inspiration and meaning-making, often emerging from their transplant experiences with a stronger faith [22] [23] [25] [28] [29] [35].

A sometimes newly found desire to perform altruistic acts was also commonly expressed [22] [23] [25] [27] [33] [35] [36]:

I used to always be one of those I, me, myself people but I would never have known or admitted it until I became sick. There had to be an incentive for everything I did and I always asked what was in it for me. But getting sick and being given a new heart has helped me realise that there is more to life than I, me, or myself. Now I focus on how I can be of help to others and how I can in simple ways return some of what was given to me when I got my new heart. ([23] p.255).

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Patients' motivation to support prospective HT-recipients in particular [27] [33] was reinforced by their belief that no one else would be qualified to perform this role: "I do not like to tell people unless they've been through something similar, because the truth is that you cannot really understand unless you've been through the same thing" ([27] p.4). It was also facilitated by their recollection of how isolated they felt before and after their transplant [25], when such support would have been especially helpful to them:

Things would have been easier for me if I had someone to share my fears with... someone who was also going through what I was going through...Now that I am feeling better, I'd like to make that possible for others...I could even share my story with them. ([23] p.254).

Over time, even those who had previously struggled often regained a sense of themselves as healthy and were increasingly able to enjoy their 'rebirth' [23] [31] [32] [36]: "Today I drive, I work, I do everything, I walk alone, I eat anything, and I feel very well. It has been almost five years and I am like I was before I had heart disease, 100% healthy" ([31] p.319). Patients described their pride in surviving their transplant experiences, thoughts that were a source of comfort and inspiration during times of struggle:

I wake up some days feeling miserable, but what matters to me is that I rose above the occasion and made it through the surgery...that was ten years ago, and I would never give up the chance that I was given to re-live my life. ([23] p.255).

Overall, this theme demonstrated the value of patients reaching a point of acceptance of their new situations. This meant harnessing their personal strengths, facing their losses, and adopting a new perspective on themselves and on life in general. Ultimately, this enabled

patients to not only tolerate ongoing difficulties but also to find satisfaction in their renewed but fundamentally altered lives.

### **Discussion**

This review sought to establish how patients psychologically experience living with a heart transplant. The synthesis generated a number of insights, both novel and confirmatory of previous research. These have important implications for how those experiencing ongoing posttransplant distress and despair might be helped. The chief findings were that, in order to psychologically recover from heart transplants, recipients had to accept that some aspects of their pre-illness physical and psychological selves were essentially irretrievable, come to terms with having a donor-heart, increase their perceived control, accept the present challenges and ongoing uncertainty, and find new meaning in their lives.

The findings highlighted barriers HT-recipients might face on the journey to psychological recovery. They might need to confront, mourn and accept a number of losses, the range of which constitutes a novel finding. These relate to their original hearts, the physical loss of which may be exacerbated by powerful cultural or religious symbolic connotations with which the heart is imbued [19], to their pre-illness lives, which might have featured careers and leisure activities that are no longer viable, and their imagined futures, which might have included having children. That the realisation of these losses may only dawn over time presents challenges for cardiac clinicians in terms of assessment.

Further potential barriers are patients' emotional responses to and beliefs about the donor, the complexity of which constitutes another novel finding. Although many participants dismissed these phenomena, this might perform an adaptive defensive function

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that becomes less necessary, less robust, or perhaps even maladaptive over time. Thus, feelings of guilt and gratitude might also emerge at any time. Facilitating the expression of these feelings in culturally and religiously sensitive ways may be an additional challenge for cardiac clinicians.

In accordance with previous findings [12], patients' lack of perceived control may be a particular barrier to psychological recovery. As posited by Hallas, Banner and Wray [18], perceived control may be especially important given its likely near-total absence during the illness that necessitated the transplant, the wait for a donor, the transplant itself, the convalescence afterwards, and the impact of the various sources of uncertainty patients described, including the (sometimes increasing) perceived threat of organ rejection. A related novel finding was that perceived control may be increased by improving the specificity and comprehensiveness of information patients receive about their treatment regimens. While providing this early may inoculate them against the shock of ongoing health problems posttransplant, patients' wish for information about such difficulties to be withheld appears to complicate this issue. This mirrors findings from a recent qualitative study that explored the experiences of cardiac patients who have received multiple ostensibly therapeutic 'shocks' from implantable cardioverter defibrillators (ICD) [42]. Participants made a strong assertion that information about the difficulties associated with shocks should be withheld from prospective ICD-recipients, partly because this would frighten them about a treatment they had no real choice but to accept.

An alternative explanation for both instances is that, prior to their respective surgeries, coping with both the more-proximal threat of having or not having the procedure and with the impact of their conditions may reduce cardiac patients' psychological resources for

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contemplating potential postoperative complications as well. After the procedures, convalescing and coping with postoperative difficulties may continue to limit these resources, prompting patients to value comprehensive information about managing their regimens but to avoid information about potential complications. The need for cardiac clinicians to find ways to sensitively but effectively prepare HT-patients for posttransplant challenges they are likely to face is a further implication of the synthesis.

Given the scope of the challenges HT-recipients face, it is perhaps unsurprising that the findings showed that psychological wellness was not achieved by patients successfully resuming the lives they led prior to becoming ill, but by discovering new meaning in their renewed but restricted posttransplant existences. Thus, a further novel implication was that the experience of successful psychological recovery from a heart transplant might best be characterised as a form of posttraumatic growth (PTG).

PTG is the phenomenon whereby the experience of trauma and adversity generates positive change [43]. Although the transplant-necessitating condition, the wait for a suitable donor, and the procedure itself are all inherently stressful, and despite research showing that posttraumatic stress disorder (PTSD) may occur in 17% of HT-recipients [44], no studies appear to have specifically investigated PTG in this population. However, the four themes identified in a recent systematic review of qualitative research pertaining to PTG following life-threatening illness [45] were all represented in the present synthesis, particularly in the fourth theme, 'The search for acceptance and new meaning'.

The four themes, and how they were reflected in the present synthesis, were as follows: 'Reappraisal of life and priorities', specifically around HT-recipients' goals, relationships and values; 'Trauma equals development of self', whereby they emerged from their transplant

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experiences with subjectively 'better', stronger, more authentic and more empathetic selves; 'Existential re-evaluation', whereby HT-recipients emerged with a different sense of the meaning and purpose of life and sometimes with reinforced or newly developed spirituality; and 'A new awareness of the body', the aspect that differentiates illness-related PTG from that resulting from other traumatic experiences and which found expression via HT-recipients' increased sense of responsibility for their health and appreciation of their re-emergent control over their bodies.

While these factors were both engines and outcomes of illness-related PTG, they may be especially important for driving not only PTG but psychological recovery in general for the HT-population; in fact, the synthesis suggests these may be tautologous concepts for this group. In the context of trauma associated with experiencing a life-threatening illness and treatment, the changes associated with PTG may be necessary if patients are to successfully adjust to the ongoing difficulties associated with posttransplant life; more so than for those recovering from isolated traumatising experiences that lack such sequelae.

Thus, PTG may not merely be an additional benefit of surviving the trauma of heart transplantation, but might in some ways be necessary in order to accommodate the durable changes necessitated by the treatment. Therefore, a proportion of those who experience ongoing psychological difficulties posttransplant may be those who have been unable to achieve the goals associated with PTG. An absence of PTG may be both causal of and consequential to the difficulties identified in extant quantitative research into posttransplant psychological difficulties, such as low hopefulness [8], avoidant/passive coping strategies [9], and lower recreational functioning, poor emotional/social support and perceived uncertainty about health [7], and may be consequential to compromised physical and

neurological functioning [7] and displaying a Type-D personality [10]. Future research could test these hypotheses by administering a battery of measures including the Posttraumatic Growth Inventory (PGI) [46] to HT-recipients and statistically analysing the results; however, a caveat is that the PGI does not include a measure of ‘new bodily awareness’, so it would not capture all of the salient data. Therefore, research could also develop an illness-related PTG measure.

### **Clinical Implications**

- As psychological difficulties may emerge at any time, periodic screening for these with standardised measures during routine consultations is likely to be advantageous, possibly as part of a care pathway that could now be developed in light of the synthesis. Using such measures also provides a pretext to enquire about any salient concerns. Although assessment may be particularly helpful at times of likely stress, such as during bouts of rejection or when a fellow HT-recipient has died, routine screening is important. Not only may life-stressors occur at any time, but also because denial of difficulties may (initially) serve an adaptive function; therefore, as people convalesce and regain control over their lives this defence may become less necessary, leaving them more vulnerable to distress. The adaptive function of denial also suggests that HT-recipients should not be pushed into acknowledging difficult feelings precipitously.
- Helping distressed HT-recipients to acknowledge, mourn and accept their transplant-related losses, and to adjust to having a donor-heart, seems important. Similarly, supporting them to gradually assume control for decisions about their medical and

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domestic care, or to at least collaborate with clinicians and family-members regarding this, would appear to be beneficial. This may necessitate specific support for families, who are likely to have been profoundly affected by their loved ones' transplant-related experiences and the illnesses that preceded them. They too may need support with letting go not just of aspects of the pre-illness loved one in question, but also of their conceptions of the sick patient they supported throughout the process. Involving the transplant co-ordination and clinical teams in these processes would be invaluable; for example, in working with patients wanting to learn more about their donor and in supporting families' adjustment. Clinical, health and counselling psychologists could provide relevant training and supervision.

- Sensitively supporting HT-recipients to find positive meaning in their lives and their transplant experiences, to develop and draw on their personal coping resources, and to increase their acceptance of the less negotiable impacts of their chronic health conditions appears likely to be beneficial. Acceptance and Commitment Therapy [47] is a psychotherapeutic modality designed to address issues of this nature and may therefore enable patients to increase their acceptance of, and meaning-making from, their posttransplant existences.
- A key element of their posttraumatic meaning-making was HT-recipients' emergent urge to perform altruistic acts, often by supporting prospective and newly transplanted HT-patients. Facilitating this would serve a dual function: recipients of support may experience a sense of hope, of being understood, and of being less

isolated, while providers' wish to help others would be satisfied. Thus, peer-mentor programmes for HT-patients may benefit not only the mentor [48], but also the mentee. However, the findings also suggested that a substantial proportion of HT-patients may prefer to decline this kind of support, so sensitivity and caution should be exercised in offering it in the absence of proper assessment of their expectations of such support.

### **Limitations**

The inclusion of papers of variable quality and with heterogeneous methodologies is a potential limitation. However, by presenting the salient characteristics of each study and the outcome of the quality appraisal, readers are able to assess for themselves the degree to which the findings are valid and applicable to specific contexts.

Only one of the studies specifically sought to capture the experience of posttransplant psychological difficulties [18] [21], and none focused on people diagnosed with psychological disorders. The experiences and associated meaning-making of such individuals may differ from those captured in the reviewed studies. Similarly, the relative lack of women across the studies means the conclusions should be tempered with particular caution with regards female HT-recipients. Research capturing the experiences of those diagnosed with psychiatric disorders posttransplant and of women is necessary to address these gaps.

### **Conclusion**

The synthesis achieved its stated objectives. Synthesising the findings from the diverse pool of studies increased their accessibility and yielded novel insights to inform psychological

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theory and the development of psychotherapeutic interventions for HT-recipients experiencing posttransplant psychological difficulties. The main findings were that these may emerge at any time posttransplant and that psychological recovery entails not only accepting a range of losses and ongoing difficulties, but may also necessitate changes that are traditionally ascribed to posttraumatic growth, such as finding new meaning in fundamentally altered lives.

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Table 1. *Salient characteristics of online databases searched*

| <b>Database</b>          | <b>Years of coverage</b> | <b>Focus</b>   |
|--------------------------|--------------------------|--|
| PsycInfo                 | 1597-Present             | Behavioural sciences and mental health                           |
| MEDLINE                  | 1946-Present             | Life sciences (with a concentration on biomedicine)              |
| Academic Search Complete | 1887-Present             | Multidisciplinary ( Humanities, Arts, Sciences, Social Sciences) |
| CINAHL                   | 1981-Present             | Nursing and allied health  |
| Web of Science           | 1900-Present             | Multidisciplinary (within social sciences)                       |

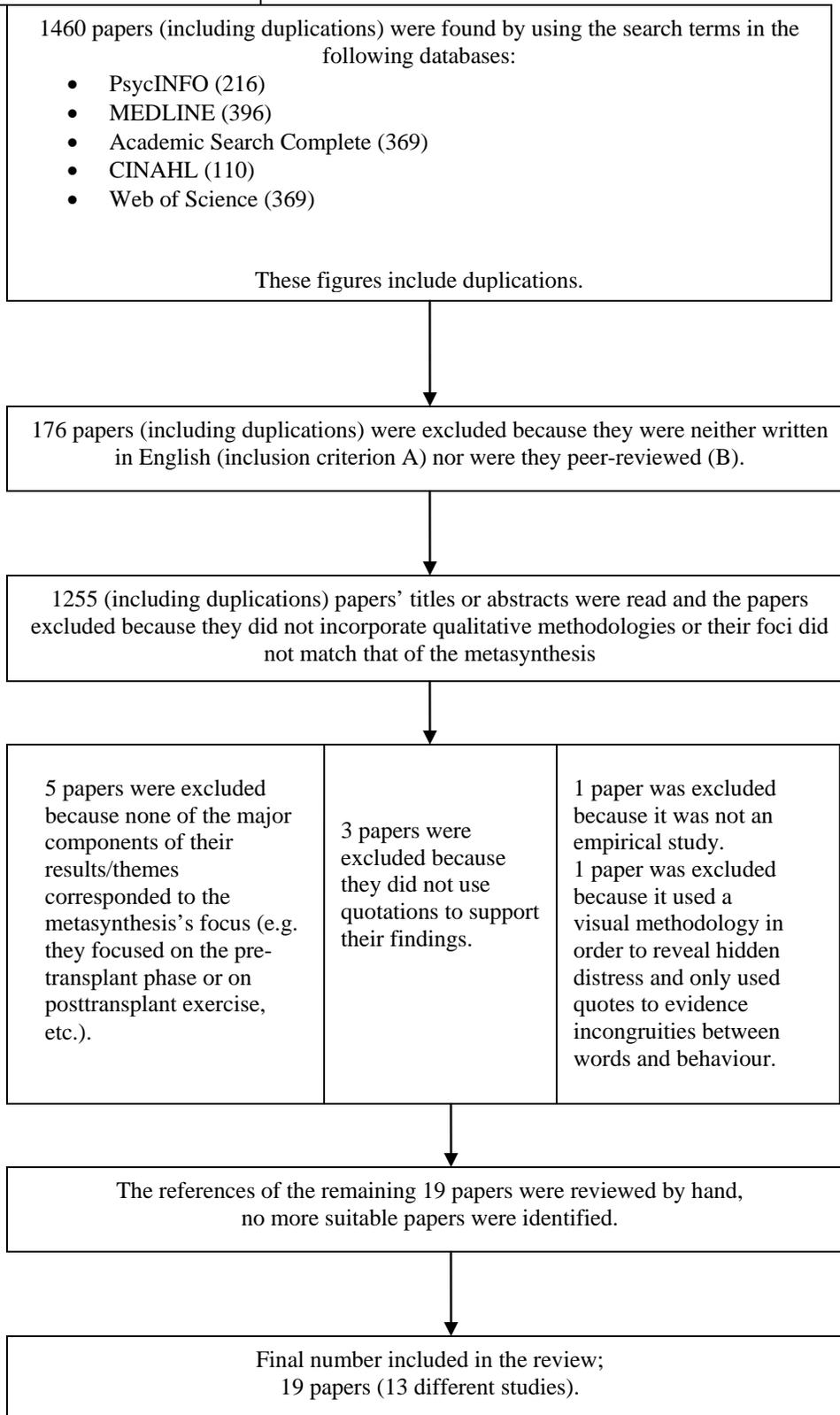
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Table 2. *Search terms used in database search engines and limiters applied*

| <b>Overall term</b>      | <b>Terms entered into each database</b>   |
|--------------------------|---|
| Heart transplant         | Heart transplant*   |
| Qualitative              | qualitative OR questionnaire* OR survey* OR interview* OR "focus group*" OR "case stud*" OR observ* OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog*  |
| <b>Database</b>          | <b>Additional limiters</b>  |
| PsycINFO                 | None  |
| MEDLINE                  | Psychology  |
| Academic Search Complete | None  |
| CINAHL                   | Psychosocial Factors.   |
| Web of Science           | [compiled from keywords of studies identified in other databases] psycholog* OR "mental health" OR "mental illness" OR adaptation OR "Attitude to health" OR distress OR "attitude to life" OR "Coping Behavior" OR "Emotional Adjustment" OR "Illness Behavior" OR "Self Perception" OR "Personality Change" OR "rehabilitation" OR "Quality of Life" OR "Social Identification" OR "Self concept" OR Stress OR Personality<br><br>[“Web of Science categories”] Transplantation |

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Figure 1. *Search strategy*



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Table 3. *CASP evaluation scores of reviewed papers*

| CASP Criteria                             | Bauman<br>n (1992) | Bunzel<br>(1992(a)<br>) | Bunzel<br>*<br>(1992(b)<br>) | Bunzel<br>*<br>(1992(c)<br>) | Kaba<br>(2000<br>) | Kaba<br>*<br>(2005<br>) | Walton<br>(2000) | Evangelista<br>(2003) | Sanne<br>r<br>(2003<br>) | Inspector<br>(2004) |
|---|--------------------|-------------------------|------------------------------|------------------------------|--------------------|-------------------------|------------------|-----------------------|--------------------------|---------------------|
| 1.Clear statement of aims                 | 2                  | 2                       | 2                            | 2                            | 2                  | 2                       | 2                | 2                     | 2                        | 2                   |
| 2.Qualitative methodology appropriate     | 2                  | 2                       | 2                            | 2                            | 2                  | 2                       | 2                | 2                     | 2                        | 2                   |
| 3.Appropriate research design             | 1                  | 1                       | 1                            | 1                            | 2                  | 2                       | 2                | 2                     | 2                        | 1                   |
| 4.Appropriate recruitment strategy        | 2                  | 1                       | 2                            | 1                            | 2                  | 2                       | 2                | 2                     | 2                        | 2                   |
| 5.Consideration of data collection        | 0                  | 1                       | 1                            | 1                            | 2                  | 2                       | 2                | 2                     | 2                        | 1                   |
| 6.Consideration of research relationships | 0                  | 0                       | 0                            | 0                            | 1                  | 1                       | 1                | 1                     | 1                        | 0                   |
| 7.Ethical Issues considered               | 1                  | 1                       | 1                            | 1                            | 2                  | 1                       | 2                | 2                     | 1                        | 1                   |
| 8.Rigorous data analysis                  | 0                  | 1                       | 1                            | 1                            | 2                  | 2                       | 1                | 1                     | 2                        | 0                   |
| 9. Findings clearly stated                | 0                  | 1                       | 1                            | 1                            | 2                  | 2                       | 2                | 2                     | 2                        | 1                   |
| 10.Value of the research                  | 2                  | 2                       | 1                            | 2                            | 2                  | 2                       | 1                | 2                     | 2                        | 1                   |
| <b>Total Score</b>                        | <b>10</b>          | <b>12</b>               | <b>12</b>                    | <b>12</b>                    | <b>19</b>          | <b>18</b>               | <b>17</b>        | <b>16</b>             | <b>18</b>                | <b>11</b>           |

\*Derived from the same study as the paper immediately to its right

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| CASP Criteria                              | Stolf & Sadala (2006) | Sadala * (2007) | Sadala * (2009) | Hallas (2009) | O'Connor (2009) | Young (2010) | Poole (2011) | Mauthner * (2012) | Ivarsson (2013) |
|--|-----------------------|-----------------|-----------------|---------------|-----------------|--------------|--------------|-------------------|-----------------|
| 1. Clear statement of aims                 | 2                     | 2               | 2               | 2             | 2               | 2            | 2            | 2                 | 2               |
| 2. Qualitative methodology appropriate     | 2                     | 2               | 2               | 2             | 2               | 2            | 2            | 2                 | 2               |
| 3. Appropriate research design             | 2                     | 2               | 2               | 2             | 2               | 2            | 1            | 2                 | 1               |
| 4. Appropriate recruitment strategy        | 2                     | 2               | 2               | 2             | 2               | 2            | 2            | 2                 | 2               |
| 5. Consideration of data collection        | 1                     | 2               | 1               | 2             | 2               | 2            | 1            | 2                 | 2               |
| 6. Consideration of research relationships | 1                     | 1               | 1               | 1             | 1               | 0            | 0            | 2                 | 1               |
| 7. Ethical Issues considered               | 0                     | 2               | 2               | 2             | 2               | 2            | 1            | 2                 | 2               |
| 8. Rigorous data analysis                  | 2                     | 2               | 1               | 2             | 2               | 2            | 1            | 2                 | 1               |
| 9. Findings clearly stated                 | 2                     | 2               | 2               | 2             | 2               | 2            | 1            | 2                 | 2               |
| 10. Value of the research                  | 2                     | 1               | 2               | 2             | 2               | 2            | 1            | 2                 | 2               |
| <b>Total Score</b>                         | <b>16</b>             | <b>18</b>       | <b>17</b>       | <b>19</b>     | <b>19</b>       | <b>18</b>    | <b>12</b>    | <b>20</b>         | <b>17</b>       |

\*Derived from the same study as the paper immediately to its right

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Table 4. *Salient characteristics of the reviewed studies*

| <b>1<sup>st</sup> Author, Title / Year / Country</b>   | <b>Aims/ Research Questions</b>  | <b>Typology</b> | <b>Method</b>   | <b>Analysis</b>   | <b>No. / age / gender / medical status (e.g. cardiac &amp; co-morbid conditions) / time since transplant [when available]</b>   | <b>Key Findings Relevant to the Review</b>   | <b>CASP score (out of 20)</b> |
|--|--|-----------------|---|---|---|--|-------------------------------|
| Baumann. Living with a heart transplant: long-term adjustment. 1992. USA.  | To better understand the experience of living with a heart transplant, using a model of chronic illness, from the perspective of both the recipient and the significant other. | Deductive       | Semistructured interviews; various quantitative measures. | None specified or described.  | n = 51; HT patients = 29; significant others = 23<br>Age of HT patients: 33-61 (mean = 49,8)<br>Sex of patients: 20 males (69%); 9 (31%) females<br>Conditions: Not reported<br>Time since transplant = 5 months-5 years (mean 22 months) | The present and future remain uncertain. Control is centrally important. Self-motivation as a barrier to recovery.   | 10                            |
| Bunzel. Does changing the heart mean changing personality? A retrospective inquiry on 47 heart transplant patients. 1992. Austria. | To explore whether heart transplant patients experience a change in personality following their operation.   | Descriptive     | Semistructured interviews                                 | An unspecified and unexplained form of qualitative analysis in which responses were grouped into three categories that emerged from the data. | n = 47<br>Age: 17-66 (mean = 47)<br>Sex: 45 males (96%), 2 females (4%)<br>Conditions: coronary disease = 12; cardiomyopathy = 23; mitral valve disease = 2 (other patients not accounted for)<br>Time since transplant = 3 months        | Most (defensively) denied any personality change. Personality changed due to surviving traumatic experiences. Personality changed because of the heart itself. | 12                            |
| Bunzel. Living with a donor heart: Feelings and attitudes of patients toward the donor and the donor organ.                        | To gain insight into heart transplant patients' feelings for and attitudes towards donor hearts and their  | Descriptive     | Semistructured interviews                                 | Identified in text as content analysis. Responses grouped into two broad categories, with numerous  | Appears to be drawn from sample used in the other Bunzel studies.<br>n = 44<br>Age: Unclear<br>Sex: 42 males (95%),   | Some avoided further information about the donor. Some aware of their denial. Some felt a distinct connection to donor. Feelings about the new                 | 12                            |

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| 1992. Austria.   | donors.  |             |                                    | sub-categories.  | 2 females (5%)<br>Conditions: coronary disease = 23;<br>cardiomyopathy = 29;<br>mitral valve = 2<br>Time since transplant = 3 months  | heart.   |    |
| Bunzel. Psychosocial Problems of Donor Heart Recipients Adversely Affecting Quality of Life. 1992. Austria.                | To evaluate the pre- and postoperative problems of HT patients from their subjective point of view.  | Descriptive | Semistructured interviews          | None specified.  | n = 47<br>Age: 17-66 (mean = 47)<br>Sex: 45 males (96%), 2 females (4%)<br>Conditions: 12 = coronary disease; 23 = cardiomyopathy; mitral valve disease = 2 (other patients not accounted for)<br>Time since transplant = 12 months | The challenges of beginning to socialise again.<br>The ongoing threat to their lives.<br>Wrestling for independence. Others' reactions made them feel different.   | 12 |
| Kaba. Coping after heart transplantation: a descriptive study of heart transplant recipients' methods of coping. 2000. UK. | To explore the coping strategies of heart transplant recipients with the intention of identifying strategies that cardiac nurses may suggest to future recipients. | Explanatory | Unstructured in-depth interviews** | Grounded theory. | n = 42<br>Age: 32-61<br>Sex: 35 males (83%), 7 females (17%)<br>Conditions: Not reported<br>Time since transplant = 2-24 months   | The need to achieve acceptance.<br>Denial of the impact of having a transplant.<br>Setting (new) targets.<br>The normalising effect of social comparisons.<br>The need to make sense of their situations.<br>The centrality of social and professional support.<br>Using faith to cope.<br>New priorities, values and perceptions. | 20 |
| Walton. "A Beacon of Light": Spirituality in the   | To identify what spirituality means to heart transplant  | Descriptive | Semistructured interviews          | Grounded theory. | n = 11<br>Age: 36-64<br>Sex: 7 males, 4   | Faith was challenged but stronger.<br>Feelings of gratitude  | 19 |

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| heart transplant patient. 2000. USA.   | patients and to identify perceptions of how spirituality influences illness and recovery.  |             |                                     |                               | females. Conditions: Not reported Time since transplant =1.5-5 years  | toward the donor. The value of supporting other (prospective) HT patients.  |    |
| Evangelista. Meaning and life purpose: The perspectives of post-transplant women. 2003. USA.   | To examine perceptions of, and meanings assigned to, the experience of end-stage heart failure and transplant surgery in female recipients.  | Descriptive | Semistructured interviews           | Qualitative content analysis. | n = 33<br>Age: 62.5 (mean); SD = 5.5<br>Sex: all females (100%)<br>Conditions: New York Heart Association Functional Classification (NYHA) – NYHA I = 70%; NYHA II = 30%<br>Time since transplant = 4.6 years (mean)  | Ongoing health concerns and treatment difficulties. Control centrally important. Faith important. Acceptance important. Altruism developed posttransplant. Perspective on life now different. | 19 |
| Sanner. Transplant recipients' conceptions of three key phenomena in transplantation: the organ donation, the organ donor, and the organ transplant. 2003. Sweden. | To explore heart/kidney transplant experiences of phenomena and identify those that distinguish these from other kinds of medical treatment. | Descriptive | Series of semistructured interviews | Not specified.                | n = 38; Heart recipients = 15 Necro-kidney recipients = 11; Living-kidney recipients = 12<br>HT Patients' age: 30-64<br>HT Patients' sex: 10 males (67%), 5 females (33%)<br>HT Patients' Conditions: Not reported<br>Time since transplant = First interview at 1-3 weeks post-transplant, | Initial euphoria gave way to grief for donor and for heart. Complicated healings for the donor emerged and evolved over time. Complicated identification with the donor.                      | 18 |

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|   |  |             |  |                                     | then several further interviews up to 2 years post-transplant.  |  |
| Inspector.<br>Another person's heart: Magical and rational thinking in the psychological adaptation to heart transplantation. 2004. Israel. | To examine heart transplant recipients' psychological adaptation to having another person's heart, with particular emphasis on their attitudes toward the heart and the donor. | Descriptive | Semistructured interviews and various quantitative measures. | Not specified.                      | n = 35<br>Age: 22-68 (mean = 50)<br>Sex: All male<br>Conditions: Gradual deterioration/numerous heart attacks = 80%; Acute deterioration = 20%<br>Time since transplant = 7 months-6 years (mean = 2 years) | Initial elation and improvement not always maintained.<br>Emotions in flux.<br>Accepting the new heart. (Fantasised) positive changes in their personality.<br>Too much and too little support.<br>Discrimination in the workplace.<br>Feelings about the donor. |
| Kaba. Somebody else's heart inside me: A descriptive study of psychological problems after a heart transplantation. 2005. UK.               | To explore heart transplant recipients' psychological adjustment and adaptation to postoperative life in order to understand more about their psychological problems.          | Explanatory | Unstructured, in-depth interviews**                          | Grounded theory.                    | n = 42<br>Age: 32-61<br>Sex: 35 males (83%), 7 females (17%)<br>Conditions: Not reported<br>Time since transplant = 2-24 months   | Feelings for the donor.<br>Fantasies about absorbing donors' characteristics. (Sometimes conscious) denial about emotional impact of receiving donor heart.  |
| Stolf.<br>Experiencing heart transplantation: the patients' perspective. 2006. Brazil.  | To understand the experience of heart transplantation from a phenomenological point of view.   | Explanatory | Semistructured interviews                                    | Phenomenological thematic analysis. | n = 26<br>Age: 13-71 (1 aged 13, 3 aged 17) (mean = 41.8)<br>Sex: 20 males (77%), 6 females (23%)<br>Conditions: Not reported<br>Time since transplant = Up to 13 years                                     | Transplant as renewal.<br>Ongoing health and treatment difficulties.<br>Life can be normal.<br>Fantasies about inheriting donor qualities.<br>Need for and challenges to autonomy.<br>Need for new meaning.<br>Gratitude to medics.                              |

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|  |   |             |                           |                                     |   | The painful loss of their own heart.  |    |
| Sadala. Heart transplantation experiences: a phenomenological approach. 2007. Brazil.                                | To understand the experience of heart transplantation from a phenomenological point of view.  | Explanatory | Semistructured interviews | Phenomenological thematic analysis. | n = 26<br>Age: 13-71 (1 aged 13, 3 aged 17) (mean = 41.8)<br>Sex: 20 males (77%), 6 females (23%)<br>Conditions: Valvar = 4; Chagas disease = 9; Idiopathic dilated cardiomyopathy = 10; Ischaemic cardiomyopathy = 2<br>Time since transplant = Up to 13 years | The transplant as rebirth. Medical regimen problematic but manageable. Ongoing uncertainty. Gratitude to the medics. Existential anxieties remain.  | 12 |
| Sadala. Heart transplantation: the experience of patients with Chagas disease. 2009. Brazil.                         | To investigate heart transplantation as experienced by patients with Chagas disease in order to understand the meanings that they attribute to such experience. | Explanatory | Semistructured interviews | Phenomenological thematic analysis. | n = 9<br>Age: 20-60<br>Sex: From Sadala et al. (2008) – 6 men (67%), 3 women (33%)<br>Conditions: Chagas disease = All participants<br>Time since transplant = Not specified, but up to 10 years, as indicated by demographics table in Sadala et al. (2008)    | The transplant is a rebirth. There is contentment in the present. The present and future are uncertain. Feelings for the donor. The experience of discrimination. Regaining autonomy is important. Newfound altruism. | 13 |
| Hallas. A qualitative study of the psychological experience of patients during and after mechanical cardiac support. | To explore issues relating to the psychological adjustment and quality of life of patients implanted with a ventricular   | Explanatory | Semistructured interviews | Grounded theory.                    | n = 11; HT patients = 3; VAD = 4; explanted = 4<br>Age (including all populations): 18-60 (mean = 42.9; SD = 13.5)  | The centrality of control. Establishing a sense of normality was crucial. Re-establishing autonomy and independence was crucial. Families   | 15 |

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| 2009. England.  | support assist device (VAD) and to compare with those of patients who have undergone heart transplantation or had the device explanted. |             |   |   | Sex (all populations): 8 males (73%), 3 females (27%)<br>Conditions (all populations): Dilated cardiomyopathy = 6; Ischaemic cardiomyopathy = 5<br>Time since transplant = 20 months (mean)                   | affected by the transplant.<br>Uncertainty continues.<br>The influence of participants' feelings and personal qualities.<br>Accepting their circumstances was helpful.                                   |    |
| O'Connor. 'I'm Cured But...': Perceptions of Illness Following Treatment. 2009. Canada.                       | To explore the posttreatment illness perceptions of a heart transplant group, a panic disorder group, and a tic disorder group.         | Explanatory | Semistructured interviews                         | Phenomenological thematic analysis, drawing on personal construct theory. | n = 13; Heart patients = 5; Panic disorder with agoraphobia = 5; Tic disorder = 3<br>Age (all populations): 18-65<br>Sex: Not reported<br>Conditions: Not reported<br>Time since transplant = Within 3 months | Centrality of independence/autonomy.<br>Ongoing limits to functioning they had to adjust to. Importance of faith. Newfound urge to behave altruistically.<br>Importance of optimism and being proactive. | 14 |
| Young. Families and heart transplantation: Reversing the trajectory of end-stage heart disease. 2010. Canada. | Explicate the social processes that impact on the health on the family members and the family unit at each stage of the HT process.     | Explanatory | Several semistructured interviews over 12 months. | Grounded theory.  | n = 15 HT patients and their families; 12 healthcare professionals<br>Age of HT patients: 24-71 (mean 52)<br>Sex: 13 males, 2 females<br>Conditions: Not reported<br>Time since transplant = Up to 12 months  | Ongoing health and treatment difficulties.<br>Finding new meaning in life. Feelings for the donor and donor's family.<br>Returning to work.  | 12 |
| Poole. The Obligation to Say 'Thank you': Heart Transplant Recipients'  | To explore heart transplant recipients' embodied responses to the   | Descriptive | Semistructured interviews                         | Unspecified visual method.  | n = 25<br>Age: 18-72 (mean = 53; SD = 13.8)<br>Sex: 17 males (70%), 8 females (30%)   | Feelings about the donor. Contacting the donor. Obligation to make contact a source of distress.   | 14 |

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|---|---|-------------|---------------------------|--|--|--|
| Experience of Writing to the Donor Family. 2011. Canada.  | 'obligation' to write a thank you letter.   |             |                           |  | Conditions: Not reported<br>Time since transplant = 1-10 years (mean = 4.1; SD = 2.4)  |  |
| Mauthner. Preparation and Support of Patients through the Transplant Process: Understanding the Recipients' Perspectives. 2012. Canada.   | To explore heart transplant recipients' thoughts on their preparation and support through the transplant process. | Descriptive | Semistructured interviews | Visual and verbal phenomenological approach. | n = 25<br>Age: 18-72 (mean = 53; SD = 13.8)<br>Sex: 17 males (70%), 8 females (30%)<br>Conditions: Not reported<br>Time since transplant = 1-10 years (mean = 4.1; SD = 2.4)   | Only HT patients could understand the experience. Remaining positive essential. Ignorance about posttransplant complications is preferable. Importance of medical professionals' support and expertise.  |
| Ivarsson. Patients' experiences of information and support during the first six months after heart or lung transplantation. 2013. Sweden. | To illuminate how patients, six months after a heart or lung transplantation.                                     | Descriptive | Semistructured interviews | Qualitative content analysis.                | n = 16; HT patients = 7 Lung transplant patients = 9<br>Age (all populations): 16-67 (mean = 51; SD = 16)<br>Sex (all populations): 7 males (44%), 9 females (56%)<br>Conditions: Cardiomyopathy<br>Time since transplant = 6 months | Ongoing health uncertainties and treatment difficulties. Importance of the medics. Financial burden increased. Participants' autonomy affected. Impact on families. Experience of discrimination. Felt unsupported by professionals in some ways. Finding new meaning in life important. Feelings towards the donor. |

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Table 5: *Noblit and Hare's (1988) seven phases of metasynthesis construction*

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|----|---|
| 1. | Deciding on the focus of the study.   |
| 2. | Selecting the papers to synthesise.   |
| 3. | Immersing oneself in the data by repeatedly reading the papers.   |
| 4. | Determining how the studies relate to each other by ascertaining similarities and differences.  |
| 5. | Translating the studies into one another by summarising then comparing their results, whilst preserving the integrity and meaning of the original findings. |
| 6. | Synthesising the translations by developing the summaries into categories.  |
| 7. | Expressing the synthesis by translating it into prose.  |

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Table 6. *Construction of a meta-theme*

| Meta-Theme title                           | Key concepts from reviewed articles.   | Key quotations  | Theme paragraph   |
|--|--|---|---|
| <b>The ambiguous presence of the donor</b> | <ul style="list-style-type: none"> <li>(Defensive) denial of any personality change.</li> </ul>                                    | <ul style="list-style-type: none"> <li>"this pile of flesh?" (Bunzel, 1992(a)).</li> <li>"Well, if that's the case, I'd have to go out chasing men from now on, wouldn't I?" (Bunzel, 1992(a)).</li> <li>"Yes, I have changed, but this, I'm sure, has nothing to do with the heart." (Bunzel, 1992(a)).</li> </ul>   | <p>This theme is about the psychological effects of losing ones heart and receiving that of a deceased person.</p> <p>Initial feelings of euphoric relief about the transplant's success eventually gave way to feelings of grief for the patient's own heart.</p>  |
|  | <ul style="list-style-type: none"> <li>Personality changed due to surviving traumatic experiences, not the donor-heart.</li> </ul> | <ul style="list-style-type: none"> <li>"Yes, I have changed. I want to avoid any kind of stress, if possible, and I have become much calmer [...] The new heart has changed me. One could say, well, not exactly, but one might put it like that: the person whose heart I got was a calm person, not hectic, and his feelings have been passed on to me now." (Bunzel, 1992(a)).</li> </ul>  | <p>Complicated feelings about the donor emerged over time, although these were often (necessarily) denied by many patients initially. Guilt about donors' deaths and gratitude towards them and their families pervaded the accounts. Patients expressed doubt about how to adequately and appropriately express their gratitude.</p>                   |
|  | <ul style="list-style-type: none"> <li>Personality changed because of the heart itself.</li> </ul>                                 | <ul style="list-style-type: none"> <li>"I wondered if I've changed. You know everybody talks about your heart, heart broken, and I wondered how much of you was within your heart, how much of your feelings. I wondered if I'll be a different person altogether because I've got somebody else's heart. You put so much feeling towards the heart, but you know your feelings are not in your heart; your feelings are, obviously, in your mind. That was something I thought a lot about. I wondered how you would feel personally, but it doesn't make a difference at all, so your feelings are not within your heart, they are within your head and I still got the same head [laughs]." (Kaba, 2005).</li> </ul> | <p>Finally, patients expressed mixed views and feelings about the potential influence of the donor-heart on their own personalities. While beliefs that such change may have happened were sometimes benign fantasies of being imbued with new positive qualities, they also reflected prejudices, self-doubt, and anxieties about organ rejection.</p> |
|  | <ul style="list-style-type: none"> <li>Depersonalisation of heart and donor</li> </ul>   | <ul style="list-style-type: none"> <li>"I know that he was 16 years of age, came from Upper Austria, and was killed in an accident. That's all. I do</li> </ul>   |   |

not think about him at all. It is absurd... Well, let's assume you wear glasses and you don't need them anymore. They fit me, and you are willing to give them to me. What sort of feeling should I have towards you and your glasses? And just as I wipe your glasses as if they are mine, I supply the heart with blood. I would say I'm not thankful to the donor but to the surgeons." (Bunzel, 1992(b)).

- Some defensively avoided further information about the donor.
  - "then I tell myself that it really is of no interest to me, because I don't really want to know it. One just doesn't know what would be at the end of that. Surely one question then leads to another and then... No, it's better not to know anything." (Bunzel, 1992(b)).
  - Some aware of their denial.
  - "otherwise I don't worry about it. Nevertheless, I also realise now how I have been looking for a justification for not thinking about it" (Bunzel, 1992(b)).
  - Some felt the donor lived on in them.
  - "I think about learning how to ride a motorcycle. Now he has turned 19, he is allowed to. I'll teach him that, too. Now the serious part of life will begin." (Bunzel, 1992(b)).
  - "We are ok" (Bunzel, 1992(b)).
  - Immediate acceptance of new heart.
  - "this is the strange thing about it, it feels as if it were mine, as if nothing organic had happened." (Bunzel, 1992(b)).
  - Concern about potential impact of contact on donor's family.
  - "I think the worst thing would be reminding them of something that hurts. You don't know how people are going to be handling something. It's been two years, but how they're handling it now. Am I going to open
-

- Challenge of living with foreign body that comes from deceased person.
    - up a new wound or am I just going to give them some joy to know that I'm still going and still doing pretty good?" (Walton).
    - "Yeah, I've tried to start a letter quite a few times. . . I don't know how it will be received. Like, I don't know if it's a . . . something that will bring back a bad memory for the family. . ." (Poole).
    - "I find it quite a spooky thought having a young man's heart inside... It's just learning to live with the thought that you've got something inside you that doesn't belong to you. I can't feel it physically, it's just psychologically, in fact it is not your own heart..." (Hallas).
    - "Today I live with the heart of someone who died...I had to see a shrink to accept that" (Stolf & Sadala).
  - Difficulty acknowledging guilt about donor and the donor's family.
    - "I don't like talking about it. I think the donor's parents are donating their son or daughter's organs, whatever they may be. I don't know who it is, and I don't want to know. I thank them that I got a heart out of it, and I'm quite happy. I feel sorry for them, but I never talk about it. I never ask any questions where the heart came from." (Kaba, 2000).
  - Gratitude towards donor.
    - "I was very grateful; I'll be indebted all my life to the chap that gave it to me and the surgeon that done it. Getting somebody else's heart; it's amazing, they put something in there that can make you better . . . I've never thought about it that way, where I got it, they told me it was a lad, maybe in his early twenties, and that was all. I didn't want to know his name or where he came from,
-

- Initial euphoria gave way to grief for donor.
  - but they told me my heart is running perfect so I was quite happy with it.” (Kaba, 2005).
  - “After the operation I was euphoric and that feeling was with me for three days. And then a strange thing happen, I started to grieve. Initially, I felt that I would have loved to have been able to speak to the people whose relative had given me the heart, you know, I felt a need to be able to thank somebody for the gift of life. And that was a barrier, that I couldn’t talk to these people . . . I haven’t really got over that. There are times when you waken up in the middle of the night and you’ve got your own thoughts and my thoughts go back to the fact that somebody had to die to give a heart. That sounds strange but not being able to actually go up to somebody and thank, that you allowed your son, daughter, your mum, your dad, whoever, for their heart to be given to me to give me this life, that was difficult. I must admit I still grieve for that person. I think about that person a lot.” (Kaba, 2005).
- Painful grief for own heart.
  - “And then I had a big problem. Well, to me, anyway, it was a big problem. I started to grieve for my own heart. That [laughs] was the strangest thing in the world, I think, isn’t it? I got really worried about what had happened to my heart; what have they done with it? You know? My heart was important to me for forty odd years and suddenly it’s away. My mum and dad gave me my heart and I’ve gave it away, what happened to it? Then I felt pretty depressed. Then nurses told me that it’s in the university

- building in a big jelly jar, it's being used for research. So, the minute I know that somebody hadn't just taken it and flung it in a big fire and burnt it, I was OK. You see I'm a Catholic, like. I know a lot of people believe in cremation but I'm not into this sort of thing. I'm going to get buried with somebody else's heart and somebody got buried without a heart, and I couldn't bear the thought of somebody taking my heart and slinging in to the fire." (Kaba, 2005).
- Obligation to make contact was a source of distress.
  - Depersonalisation strategy used by medics.
  - (Fantasised) positive changes in their personality.
  - Ongoing sense of loss for own heart.
  - Avoidance of gratitude towards donor.
- "(It) was a little more painful, simply in that. . .because I got to learn about this person. . .although they were realistic before, but all of a sudden they have a family. . .it changes things" (Poole).
  - "The doctors talked about it as if the stock was out of supply for the moment and they were soon expecting a new delivery" (Sanner).
  - "I, at the time of the transplant was 51 years old. And I received the heart of a youth of 18. That is, of course... I became young again. Today I am 22 years old, aren't I? When I have lived another 50 years, I will be one hundred years old or so!" (Stolf & Sadala).
  - "You will always keep that in mind. That I live, today, I no longer live with my own heart; this is the case. It will never be the same thing. The heart, it beats fast, faster. You will never be what you were before" (Stolf & Sadala).
  - "refusal to turn into a living monument of the donor." (Inspector)
-

- Incredulous about operation and immediately accepting of heart as ones own.
  - “I am grateful for it ... it is really amazing that you can do it. Mostly I think of it as my heart, you don't think of it as someone else's.” (Ivarsson).
  - Feeling unworthy of the transplant.
  - Guilt about hoping for a donor.
  - Guilt led to fears of organ rejection.
  - Denial defence decreased over time.
  - Feelings and thoughts towards the donor expressed soon after the transplant.
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|  | <p>Personality change: attitudes towards: critical/positive/negative/donor-heart-related/trauma-related (no</p> | <p>fit me, and you are willing to give them to me. What sort of feeling should I have towards you and your glasses? And just as I wipe your glasses as if they are mine, I supply the heart with blood. I would say I'm not thankful to the donor but to the surgeons.” [20]</p> <p>“I couldn’t come to terms with that very easy, the thought of getting somebody else’s heart. I used to lose sleep at night because I was thinking there was a healthy person somewhere that had an accident and gave you a heart, and that used to make me lose a lot of sleep.” [30]</p> <p>“I was very grateful; I’ll be indebted all my life to the chap that gave it to me” [30]</p> <p>“[My] refusal to be a living monument of the donor” [25]</p> <p>“I think the worst thing would be reminding them of something that hurts. You don't know how people are going to be handling something. It's been two years, but how they're handling it now. Am I going to open up a new wound or am I just going to give them some joy to know that I'm still going and still doing pretty good?” [22]</p> <p>“(It) was a little more painful, simply in that...because I got to learn about this person...although they were realistic before, but all of a sudden they have a family...it changes things” [26]</p> <p>“This pile of flesh?” [19]</p> <p>“Yes, I have changed. I want to avoid any kind of stress, if possible, and I have become much calmer [...] The new heart has changed me. One could say, well, not exactly,</p> |
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|                                 | quote)  | <p>but one might put it like that: the person whose heart I got was a calm person, not hectic, and his feelings have been passed on to me now.” [19]</p> <p>“men are stronger” [24]</p> <p>“I think about learning how to ride a motorcycle. Now he has turned 19, he is allowed to. I’ll teach him that, too” [20]</p>  |
| Reborn but still not in control | <p>Transplant was rebirth</p> <p>Ongoing uncertainty and loss of control: health and treatment regime</p> | <p>“When I awoke from that surgery, it was as if you realise what it is to be reborn. It is as if you are free from all those problems, you will restart all again” [31]</p> <p>“My health is not completely stable...I feel good sometimes, then it gets knocked back down.” [36]</p> <p>"[The posttransplant period was like going] from Heaven to Hell" [21]</p> <p>“so far the medications seem to be doing their job" [18]</p> <p>“there are difficulties and I need to be careful” [35]</p> <p>“Rejection: Just the word scares me that I’ll die before I do all the things I want to do yet. Having to go through an annual admission every year, I hate those three days and wondering what the results will be. I feel more anxious and worried about rejection and serious side effects of the medications as I get farther from the transplant...sort of wondering how long can my luck hold?“ [18]</p> <p>“It seems that you are expecting that something is going to happen, and then you feel it won’t happen, you</p> |

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|  | <p>Lack of self-motivation/control</p> <p>Uncertainty about finances</p> <p>Lack of control over their emotions</p> <p>Autonomy within the home/</p> <p>Reducing uncertainty about health: avoidance of other patients/avoidance of information about complications</p> | <p>know...Then it seems that you live on a tight rope” [32]</p> <p>"Five of us were transplanted successively. Three of us are dead. And now I am in hospital...Who will be the next one to go?" [21]</p> <p>“Laziness and lack of motivation are my problem. I know I should be exercising but I just can't get myself going. Also it's hard to exercise alone. It would be easier if I had someone to do it with or a class, but that's too expensive. I just can't afford it.” [18]</p> <p>"[The transplant] improved my heart and health, but caused lots of financial problems" [18]</p> <p>“the transplant "improved the physical side of things [...] emotionally there's more anxiety, wondering if I will stay healthy, fear of rejection, future very uncertain" [18]</p> <p>No quotes</p> <p>“Well, you have to encourage this person...never tell them...’Oh, my God, you know, tomorrow you are going to be worse’, never say that to the person who went through a nightmare...never discourage people.” [27]</p> <p>“I personally do not like having any contact with them because they would moan and they had different aches and pains, the things that I've got to go through, and sometimes I think its better not knowing what lies ahead” [29]</p> |
| <p>Striving for autonomy and normality</p> | <p>Autonomy and normality: Basic skills</p>   |  |

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|  | <p>Taking responsibility for their health</p>                                    | <p>“One needs to take responsibility for his or her health and that begins with understanding what is expected of you in terms of medications, diet, and exercise” [23]</p>   |
|  | <p>Managing their emotions</p>   | <p>“I found I didn't want to see anything hurtful. I couldn't read the paper, you know, the Bosnia situation...I didn't want to think about it too deeply. I didn't want to hear anything nasty that there were children being abducted, raped, and all these things. I didn't want to know about it. It was almost as if I was an open wound and it would hurt too much [...] It was enough just to be coping with my situation.” [29]</p> |
|  | <p>Comparison with worse possible situations</p>                                 | <p>“I definitely put a hell of a strain on the family but I don't think it would be as much strain on the family as if I had snuffed it. I think that would have been a bigger strain, if I died without this transplant. [29]</p>  |
|  | <p>Socialising – importance and challenges</p>                                   | <p>“For my neighbours I have become a mixture of miracle and zombie” [21]</p> <p>“I lost a lot of friends and that's hurts me quite a bit. [...] I don't go out socially, I stay in. I don't have any social life” [29]</p>   |
|  | <p>Resuming former domestic and employment roles – importance and challenges</p> | <p>“Many people at that time said: ‘You can retire because you transplanted.’ But I did not want to, I continued working. I work until today.” [31]</p> <p>I couldn't do a lot before I got my heart. He carried the load for me, the house and everything. And taking over the bills, and I just couldn't handle the stress of anything anymore. So he took over, and he did such a good job,</p>  |



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|  |  | <p>himself go. For me it's a complete waste of a transplant because he is not doing anything with his life. He should be out enjoying himself but he sits there and almost vegetates, which is sad.” [29]</p> <p>“Sure, [my family] did not always have the health we wanted or the money we needed, but we didn’t let that affect us...You just learn to accept what you can do and make adjustments for what you cannot do...I’m just happy to be alive...there are so many things that you are able to do and to experience when you have more life.” [23]</p> <p>“There must be a reason. There's a reason for everything in this world. I firmly believe that there's a reason why I've gone through what I've done and come out at this end. There must be a reason and maybe eventually it will be unfolded to me.” [29]</p> <p>“I'm paying the price of being a bad boy all my years” [29]</p> <p>“I used to always be one of those I, me, myself people but I would never have known or admitted it until I became sick. There had to be an incentive for everything I did and I always asked what was in it for me. But getting sick and being given a new heart has helped me realise that there is more to life than I, me, or myself. Now I focus on how I can be of help to others and how I can in simple ways return some of what was given to me when I got my new heart.“ [23]</p> <p>“I do not like to tell people unless they’ve been through something similar, because the truth is that you cannot really understand unless you’ve been through the same</p> |
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|  | <p>Eventual transcendence and robustness</p> | <p>thing” [27]</p> <p>“Things would have been easier for me if I had someone to share my fears with... someone who was also going through what I was going through...Now that I am feeling better, I’d like to make that possible for others...I could even share my story with them.“ [23]</p> <p>“Today I drive, I work, I do everything, I walk alone, I eat anything, and I feel very well. It has been almost five years and I am like I was before I had heart disease, 100% healthy” [31]</p> <p>“I wake up some days feeling miserable, but what matters to me is that I rose above the occasion and made it through the surgery...that was ten years ago, and I would never give up the chance that I was given to re-live my life.“ [23]</p> |
|--|--|--|

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Table 8. *Meta-themes and contributing papers.*

| Meta-Theme                  | Baumann (1992) | Bunzel (1992(a)) | Bunzel * (1992(b)) | Bunzel * (1992(c)) | Kaba (2000) | Kaba * (2005) | Walton (2000) | Evangelista (2003) | Sanner (2003) | Inspector (2004) |
|-----------------------------|----------------|------------------|--------------------|--------------------|-------------|---------------|---------------|--------------------|---------------|------------------|
| Ambiguous presence of donor |                | x                | x                  | x                  | x           | x             | x             |                    | x             | x                |
| Reborn but not in control   | x              |                  |                    | x                  | x           |               |               | x                  | x             | x                |
| Autonomy and normality      |                |                  |                    | x                  | x           |               | x             | x                  |               | x                |
| Acceptance and new meaning  |                |                  |                    |                    |             | x             | x             | x                  |               | x                |

| Meta-Theme                  | Stolf & Sadala (2006) | Sadala * (2007) | Sadala * (2009) | Hallas (2009) | O'Connor (2009) | Young (2010) | Poole (2011) | Mauthner * (2012) | Ivarsson (2013) |
|-----------------------------|-----------------------|-----------------|-----------------|---------------|-----------------|--------------|--------------|-------------------|-----------------|
| Ambiguous presence of donor | x                     | x               | x               | x             |                 | x            | x            |                   | x               |
| Reborn but not in control   | x                     | x               | x               | x             | x               | x            |              | x                 | x               |
| Autonomy and normality      | x                     | x               | x               | x             |                 | x            |              |                   | x               |
| Acceptance and new meaning  | x                     | x               | x               | x             | x               | x            |              | x                 | x               |

\* Indicates papers derived from same study as the paper immediately to their left.

## Appendix 1-A

### European Journal of Cardiovascular Nursing - Author guidelines

*European Journal of Cardiovascular Nursing* publishes original articles, short report reviews and editorials in order to improve the quality of nursing care for patients with cardiovascular disease. Original contributions on the broad field of cardiovascular nursing are welcome, including chronic and acute care, paediatric cardiology, grown up congenital heart disease, cardiac rehabilitation, primary and secondary prevention, heart failure, acute coronary syndromes, interventional cardiology, cardiac care, preventive cardiology, and vascular nursing.

Scientific contributions can be related to all aspects of care: education, research, patient care or organisational aspects. Additional contributions on epidemiology, physiology, pharmacology or psychology related to cardiovascular nursing are welcome.

#### 1. Peer review policy

Manuscripts are normally evaluated by three members from an international panel of reviewers. An editorial decision is normally taken within 28 days of receipt of a manuscript.

Please submit, with the manuscript, the names, addresses and e-mail addresses of three potential referees. Note that the editor retains the sole right to decide whether or not the suggested reviewers are used.

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#### 2. Article types

##### 2.1 Regular papers

The text should be arranged as follows: (1) Title Page, (2) Abstract, (3) Keywords, (4) Introduction, (5) Methods, (6) Results, (7) Discussion, (8) Implications for Practice, (9) Acknowledgments, (10) References, (11) Figures and Tables.

The maximum length for regular papers is **3,500 words**.

**(1) Title page:** Please include the following:

**Title:** Concise and informative. Avoid abbreviations and formulae where possible.

**Author names and affiliations:** Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

**Corresponding author:** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.

**Present/permanent address:** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

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**(2) Abstract:** An abstract (maximum 250 words) should be typed double spaced on a separate page. It should be structured and include background, aims, methods and results and conclusion.

**(3) Keywords:** No more than six keywords are required.

**(4) Introduction:** This section should position the study with regard to objective, rationale and preceding work of other authors.

**(5) Methods:** This section should contain a statement that "The investigation conforms with the principles outlined in the Declaration of Helsinki" (Br Med J 1964;ii:177). The methods section should be sufficiently detailed for repetition of the study by other scientists. If pertinent, the section may be divided into headed subsections.

**(6) Results:** If pertinent, the section may be divided into headed subsections. For presentation of data, figures are preferred to tables. Data should not be presented in both figures and tables. Also, extensive numerical data should appear in legends to the figures rather than in the main body of text. SI units should be used.

**(7) Discussion:** This section should deal with topics that are beyond the scope of the study, compare and interpret the data with regard to previous work by (other) authors.

**(8) Implications for Practice:** Please provide three to five key bullet points that summarise the implications of their paper for practice. The aim of these is to encourage others to use the findings in their daily practice of patient care, education or research based on the stated points. Please ensure each bullet is no longer than 50 characters. These bullet points will be published as part of the article.

### **(9) Acknowledgments**

### **(10) References**

**(11) Figures and Tables:** Figures should be designed in a way compatible with reproduction of one column width. Figures over two columns should be kept to a minimum. Please avoid very large tables of data if possible. Larger tables could be published as supplementary data on the Journal's website (see section 8.4 Manuscript Preparation below). Tables should not contain data not mentioned in the text. Laser prints of good quality are sufficient for graphs and tables. Glossy prints are needed for micrographs, etc. Figure legends should start on a new page of the manuscript, but one page may contain legends to more than one figure.

## **2.2 Short Reports**

These reports **should not exceed 2,000 words** and should consist of:

- Background section
- Abstract
- Methods
- Results
- Conclusion

The (maximum number of) 2,000 words may be allocated as you consider appropriate. The editorial team reserves the right to decide which tables/figures submitted are necessary.

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### 3. Authorship

Papers should only be submitted for consideration once the authorization of all contributing authors has been gathered. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all those who:

- have made a substantial contribution to the concept and design, acquisition of data or analysis and interpretation of data,
- drafted the article or revised it critically for important intellectual content,
- approved the version to be published.

Authors should meet the conditions of all of the points above. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section.

Please refer to the [ICMJE Authorship guidelines](#).

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All papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

A covering letter should include a declaration that "the manuscript, or part of it, has neither been published (except in the form of abstract or thesis) nor is currently under consideration for publication by any other journal". Secondly, the submitting author should declare that the co-author(s) has (have) read the manuscript and approved its submission to the *European Journal of Cardiovascular Nursing*.

Please note that manuscripts will not be returned unless a specific request is made at the time of first submission.

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#### 6.1 Acknowledgements

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

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Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of the *European Journal of Cardiovascular Nursing* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

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### **6.4 Other statements and conventions**

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All randomized controlled trials submitted for publication in *Public Health* should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart. Please refer to the CONSORT statement website at <http://www.consort-statement.org> for more information.

Manuscripts that fail to comply with the CONSORT guidelines will not be reviewed for publication.

#### **6.4.2 Research ethics**

All papers reporting animal and human studies must include whether written consent was obtained from the local Ethics Committee or Institutional Review Board. **Please ensure that you have provided the full name and institution of the review committee and an Ethics Committee reference number.**

We accept manuscripts that report human and/or animal studies for publication only if it is made clear that investigations were carried out to a high ethical standard. Studies in humans which might be interpreted as experimental (e.g. controlled trials) should conform to the Declaration of Helsinki <http://www.wma.net/en/30publications/10policies/b3/index.html> and typescripts must include a statement that the research protocol was approved by the appropriate ethical committee. In line with the Declaration of Helsinki 1975, revised Hong Kong 1989, we encourage authors to register their clinical trials (at <http://clinicaltrials.gov> or other suitable databases identified by the ICMJE, [http://www.icmje.org/publishing\\_10register.html](http://www.icmje.org/publishing_10register.html)). If your trial has been registered, please state this on the Title Page. When reporting experiments on animals, indicate on the Title Page which guideline/law on the care and use of laboratory animals was followed.

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Authors are required to ensure the following guidelines are followed, as recommended by the International Committee of Medical Journal Editors, Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published.

Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent should be obtained if there is any doubt. For example, masking the eye

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region in photographs of patients is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic pedigrees, authors should provide assurance that alterations do not distort scientific meaning and editors should so note. When informed consent has been obtained it should be indicated in the submitted article.

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### 8. Manuscript style

#### 8.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

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The *European Journal of Cardiovascular Nursing* conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

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The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#).

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Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented

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separately to the main text of the article to facilitate anonymous peer review. Contact details must be kept up to date by the corresponding author.

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- Make sure you use uniform lettering and sizing of your original artwork.
- Save text in illustrations as 'graphics' or enclose the font.
- Only use the following fonts in your illustrations: Arial, Courier, Times, Symbol.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Produce images near to the desired size of the printed version.
- Submit each figure as a separate file.

#### **Please do not:**

- Supply files that are optimised for screen use (e.g., GIF, BMP, PICT, WPG); the resolution is too low.
- Supply files that are too low in resolution.
- Submit graphics that are disproportionately large for the content.

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## 10. Further information

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### 1. General

1. Reference numbers have full points in the reference list.
2. Please ensure that publications are referenced in the order in which they appear in the text.
3. Journal titles should be abbreviated according to the standard in the Index Medicus. If unsure, please check for any inconsistencies within reference lists. For STM journals, please refer also to the following: <http://scieng.library.ubc.ca/coden/>.
4. Do not separate initials with spaces or full points, but add a full point after last initial before the title.
5. Up to three authors may be listed. If more, then list the first three authors and represent the rest by et al. Fewer author names followed by et al. is also acceptable. Where et al. is used, it should always be upright, not italic in both references and textual citations.
6. Last Names containing de, van, von, De, Van, Von, de la, etc. should be listed under D and V respectively. List them as: De Roux DP and not Roux DP, de. When cited in the main text without the first name, use capitals for De, Van, Von, De la, etc. (Van Dijk, year)
7. Names containing Jr or II should be listed as follows:
  - Author Last Name Initial Jr (year)
  - Author Last Name Initial II (year)

### 2. Text citations

Please use superscript numerals *after* the punctuation (STM) or numbers in square brackets (HSS), and check that it corresponds to the correct number in the reference list.

### 3. Reference styles

#### Book

1. Huff D. *How to lie with statistics*. 4th ed. London: Penguin, 1991, p.51.

#### Chapter in book

1. Huff D and Black TL. Comprehensive statistics. In: Miller C and Smith H (eds) *How to lie with statistics*. 4th ed. London: Penguin, 1991, pp.51–55.

#### Journal article

1. Ludbrook J, Miller T and Russel A. Musculo-venous pumps in the human lower limb. *Am Heart J* 1966; 71: 635–641.

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2. Araki C, Black TL, Patberg FT, et al. Significance of calf muscle pump function in venous ulceration. *J Vasc Surg* 1994; 20: 872–879.

*Journal article published ahead of print*

1. Ludbrook J. Musculovenous pumps in the human lower limb. *Am Heart J*. Epub ahead of print 12 June 2011. DOI: 10.1177/095443271167940.

*Website*

1. Smith JR. Choosing your reference style. *Online Referencing* 2(3), <http://orj.sagepub.com> (2003, accessed 12 October 2008).

2. National Center for Professional Certification. Factors affecting organizational climate and retention, [www.cwla.org/programmes/triechmann/2002fbwfiles](http://www.cwla.org/programmes/triechmann/2002fbwfiles) (2002, accessed 10 July 2010).

*Conference paper*

1. Peters J. Musculovenous pumps in the human lower limb. In: *ASME conference on automatic transmissions* (ed A O'Brien), Pisa, Italy, 29 May–2 June 2003, paper no. GE1234, pp.4–10. New York: ASME.

*Thesis/dissertation*

1. Clark JM. *Referencing style for journals*. PhD Thesis, University of Leicester, UK, 2002.

*Patent and patent applications*

1. Smith ST. *Referencing styles for journals – a new method*. Patent 12346-ZH, USA, 2011.

2. Jones P. *Referencing styles for journals – a new method*. Patent application 12346-ZHA, USA, 2011.

*Report (published/unpublished)*

1. MacDonald S. The state of social welfare in the UK. Report, University of Durham, UK, June 2011.

2. Citigroup Ltd. *How to make your money work for you*. Report for the Department of Finance. Report no. 123345, 13 June 2011. Oxford: OUP.

*SAE/JSAE etc. papers*

1. Clark JM. A new exhaust gasket manifold for powertrains. SAE paper 2002-0101234, 2002.

*Newspaper/magazine*

1. Clark JM. Referencing style for journals. *The Independent*, 21 May 2006, p.10.

*Package insert (medical etc.)*

1. Eisai Inc. Aloxi (package insert). New York: Eisai Inc, 2008.

*Manual (automotive etc.)*

1. Fiat. Driver's manual, Fiat Uno 4-litre diesel model, December 2010.

*Standard*

1. ISO 27799:2008. Information security management in health.

Tip!

See various sites for more information on Vancouver and journal abbreviations:

<http://www.library.uwa.edu.au/students/guides>

<http://www2.le.ac.uk/library/help/citing/managinginformation>

<http://scieng.library.ubc.ca/coden/>

[http://www.wsulibs.wsu.edu/general/journal\\_abbreviations.html](http://www.wsulibs.wsu.edu/general/journal_abbreviations.html)