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# BMJ Open

## The Healing Journey

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# The Healing Journey

John G. Scott, MD, PhD<sup>1,6</sup>

Sara L. Warber MD<sup>2,3</sup>

Paul Dieppe, MD, FRCP, FFPH<sup>3</sup>

David Jones, MD<sup>4</sup>

Kurt C. Stange, MD, PhD<sup>5</sup>

1 Northeastern Vermont Regional Hospital, Corner Medical, 195 Industrial Parkway Box 53,  
Lyndonville, Vermont 05851. Email: [john.gleenn.scott@gmail.com](mailto:john.gleenn.scott@gmail.com). Telephone: 802-748-9501-  
Ext 225 Fax: 802-748-3420

2 Department of Family Medicine, University of Michigan Medical School, Ann Arbor,  
Michigan

3 University of Exeter Medical School, Exeter, UK

4 The Institute for Functional Medicine

5 Departments of Family Medicine & Community Health, Epidemiology & Biostatistics, and  
Sociology; Case Comprehensive Cancer Center, Cleveland Clinical & Translational Science  
Collaborative, Case Western Reserve University, Cleveland, Ohio

6 Department of Community and Family Medicine, Dartmouth Geisel School of Medicine,  
Hanover, New Hampshire

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## Abstract

**Objectives:** To elucidate pathways to healing for people having suffered injury to the integrity of their function as a human being.

**Methods:** A team of physician-analysts conducted thematic analyses of in-depth interviews of 23 patients who experienced healing, as identified by six primary care physicians purposefully selected as exemplary healers.

**Results:** People in the sample experienced healing journeys that spanned a spectrum from overcoming unspeakable trauma and then becoming healers themselves, to everyday heroes functioning well despite ongoing serious health challenges.

The degree and quality of suffering experienced by each individual is framed by contextual factors that include personal characteristics, timing of their initial or ongoing wounding in the developmental life cycle, and prior and current relationships.

In the healing journey, bridges from suffering are developed to healing resources/skills and connections to helpers outside themselves. These bridges often evolve in fits and starts, and involve persistence and developing a sense of safety and trust.

From the iteration between suffering and developing resources and connections, a new state emerges that involves hope, self-acceptance, and helping others. Over time this leads to healing that includes a sense of integrity and flourishing in the pursuit of meaningful goals and purpose.

**Conclusion:** Moving from being wounded, through suffering to healing, is possible. It is facilitated by developing safe, trusting relationships, and by positive reframing that moves through the weight of responsibility to the ability to respond.

## Strengths and limitations of this study

### Strengths

- Subjects were selected to maximize probability that they have experienced healing
- Data consist of long rich interviews with subjects
- This is one of few studies to examine healing from the patient perspective
- Qualitative analysis done by a diverse team
- Analysis used to generate a theoretical model of how patients experience healing
- This model may give guidance and hope to people experiencing illness and suffering
- The model may help clinicians understand their limited but important role in patients' healing journeys.
- The validity of our analysis is enhanced by the training and experience of the analysis team, reflexivity (reflecting on our own experiences), and searching the data for disconfirming evidence after we identified themes.

### Limitations

- Because subjects were selected for their experience of healing, they are likely to not be representative of ill people in general
- We do not presume that healing always happens or is even always possible
- It is possible that the path to healing is affected by sex, race, ethnicity, and a host of other factors that were not apparent in our small sample. Thus, our findings cannot be used to generalize about the effects of demography, time, place or culture.

- Our interpretation of these data is inevitably influenced by our life experience.

## Introduction

As medicine moves away from the Cartesian reductionism that considers patients as collections of organ systems and deposits of diseases,<sup>1</sup> there has been much interest in how medical professionals can foster healing.<sup>2</sup> The word “healing” comes from the Old English *haelan* meaning “whole” and alludes to a process that brings wholeness in physical, emotional, intellectual, social, and spiritual aspects of self.<sup>3</sup> There are several definitions of healing in the medical literature. Csordas describes healing as a transformational change.<sup>4</sup> Egnew talks of transcending suffering.<sup>6</sup> Kirmayer describes it as a journey from feeling ill to wellness.<sup>5</sup> Hsu and colleagues<sup>6</sup> emphasize recovery and regaining a sense of balance and peace. Cassel defines healing as “making whole again.”<sup>2,7</sup> Scott et al describe it as being cured when possible, reducing suffering when cure is not possible, and finding meaning beyond the illness experience.<sup>8</sup> All of these definitions have in common the idea of recovering a sense of integrity and wholeness after experiencing illness and suffering. This synthesis is the definition of healing that we used in our analysis.

In 2001 the Institute of Medicine included the “development of continuous healing relationships” as their first priority in improving the quality of medicine.<sup>9</sup> The nursing literature has been particularly important in theoretical development and empirical studies related to nurse-patient relationships, especially with regards to caring.<sup>10,11</sup> Studies on healing relationships between doctors and patients have focused on interviews with physicians<sup>7,12,13</sup> or patients<sup>14</sup> or both.<sup>6,8</sup> While this focus on healing relationships between health professionals and patients is useful for health professionals, what is missing from this literature is a description of the

1  
2  
3 experience of people who are ill and how they manage to find healing. Eric Cassels describes the  
4  
5 dilemma we continue to face: "...from all this, we would have to conclude that it is not known  
6  
7 what the basis of healing is, BUT also there is little doubt that there really is something called  
8  
9 healing."<sup>2</sup>  
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13 Although there is a literature on patients' experience of healing, it consists primarily of  
14  
15 anecdotal reports (pathographies) by individuals describing their personal experiences with  
16  
17 illness and healing.<sup>15</sup> There are a few systematic qualitative studies of healing from the patient  
18  
19 perspective in the nursing literature, but all of these describe healing from specific illnesses.<sup>16-20</sup>  
20  
21 Verhoef and Mulkins did a qualitative analysis of the healing experiences of patients with a  
22  
23 diversity of diseases, but this was limited to patients attending integrative clinics that included  
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25 complementary and alternative practitioners.<sup>21</sup>  
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30 Because of a continued need for deeper understanding of the process of healing from the  
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32 point of view of the person experiencing it, this study was undertaken to explore pathways to  
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34 healing for people who have been wounded by serious illness and/or life events and who access  
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36 care through the conventional health system.  
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## 43 **Methods**

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46 We did a qualitative analysis of transcripts of long interviews with 23 people who had  
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48 experienced healing. This was a secondary analysis of data originally collected by Scott, et al in  
49  
50 their study of healing relationships between doctors and patients.<sup>8</sup> That study included physician  
51  
52 interviews as well and focused on how doctors and patients experienced their relationships with  
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54 each other. In this study we used only the patient interviews, which contained rich descriptions  
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3 of pathways to healing.  
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### 6 7 Sampling Strategy 8

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10 As described in more detail by Scott et al,<sup>8</sup> physicians believed to be exemplars in  
11 developing and maintaining healing relationships were purposefully selected based on an  
12 assessment of publications, reputation, and awards. Each physician was interviewed and also  
13 asked to identify 3-6 adult patients whom they perceived to have experienced healing. These  
14 patients constitute the sample for the current study. This sampling strategy was designed to  
15 maximize the probability of finding the phenomenon we wished to study; that is people who had  
16 experienced healing.  
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### 26 27 Interviews 28

29  
30 After obtaining informed consent, the first author conducted face-to-face in-depth  
31 interviews with patients according to a semi-structured interview guide\* that contained several  
32 grand tour questions<sup>22</sup> designed to elicit healing stories from the subjects. The interview guide  
33 included questions about healers other than physicians as well as questions about what patients  
34 bring to healing relationships. Interviews lasted 1 to 3 hours, and were conducted at places of  
35 the subjects choosing, most commonly in their homes, but some at their physician's office and  
36 some at restaurants or other venues chosen by the subjects. The interviews were recorded and  
37 transcribed. Transcripts were checked for accuracy and were imported into qualitative analysis  
38 software, Atlas-ti.<sup>23</sup> The Robert Wood Johnson Medical School Institutional Review Board  
39 approved the original study,<sup>8</sup> and determined that further research using de-identified transcripts  
40 would not require institutional review board review.  
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58 \* See [http://www.annfamned.org/content/suppl/2008/07/07/6.4.315.DC1/Scott\\_App\\_1-2.pdf](http://www.annfamned.org/content/suppl/2008/07/07/6.4.315.DC1/Scott_App_1-2.pdf)  
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## Analysis

The analysis team consisted of a family physician with 21 years' experience in private practice as well as extensive experience in qualitative research and analysis (JGS), two practicing family physicians from large academic medical centers, both of whom have qualitative research experience (KCS) and (SLW), a rheumatologist/health services researcher from an academic medical center in the United Kingdom who is undertaking research on healing (PD), and a practicing family physician from the west coast of the U.S. who was instrumental in developing the concepts, knowledge base and tools for the clinical application of functional medicine<sup>24</sup> (DJ).

Analysis proceeded iteratively,<sup>22</sup> using a combination of editing<sup>25</sup> and immersion/crystallization<sup>22</sup> approaches. These qualitative methods are a modification of a grounded theory approach to analysis<sup>26</sup> that has been well documented by Crabtree and Miller.<sup>27</sup> Over several months, the analysis team individually read the interviews. The interviews were then discussed as a group via a number of conference calls. One member served as primary analyst for each interview, producing an initial summary and thematic analysis supported by representative quotations, and refining this case analysis as the group discussion produced confirming or disconfirming data and additional interpretations.

Case studies were analyzed to identify common themes. Finally, at a three-day intensive retreat, the analysis team extensively discussed these themes, referring back to the original data and case summaries for confirming and disconfirming evidence. This analysis was used to develop a model of pathways to healing.

## Results

### The participants

A total of 23 participants, identified by their physicians as people who had experienced healing, were interviewed. Their ages ranged from 30-86 at the time of interview (mean 58); 14 were female and 9 male; 17 were White, 4 Hispanic and 2 Black; 14 were of high socioeconomic status, 4 mid and 5 low.

Participants had a complex mixture of medical, psychological and social issues, which included: myocardial infarction, congestive cardiac failure, inflammatory bowel disease, cancer, diabetes, chronic pain, HIV infection, substance abuse, obsessive-compulsive disorder, incest and sexual abuse. Most of the interviewees had more than one problem.

### The healing journeys

Analyses revealed that healing was not an isolated event that happened at a particular point in time. Rather, healing typically took place in fits and starts over an extended period of time. This process was not linear and not predictable. The path to healing was different for each person. The metaphor of a journey emerged as an apt description of this process, because that was how the subjects talked about their experiences of healing. These journeys spanned a spectrum from overcoming unspeakable trauma (sexual abuse by a parent for example) and then becoming healers themselves (therapist, social worker for example), to everyday heroes functioning despite ongoing health challenges (for example – functioning in family and daily life despite enduring chronic pain from inflammatory bowel disease). During their journeys all the

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2  
3 subjects experienced suffering, defined as the experience of distress when the intactness or  
4  
5 integrity of the person is threatened.<sup>2</sup>  
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### 8 9 Major Themes that Describe the Healing Journey

#### 10 11 12 CONNECTIONS OUTSIDE ONESELF

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14  
15 Connection to others was an essential part of all the healing journeys. As one person said,  
16  
17 *“Once I started connecting with people, I started healing.”* (participant 11)  
18  
19

20  
21 People experiencing healing developed relationships with many kinds of helpers.  
22  
23 Relationships with health professionals were among these, but were not necessarily any more  
24  
25 important to the healing journey than other kinds of helpers, which included family members,  
26  
27 friends, spirituality and their God, pets, support groups, administrators, case workers and  
28  
29 supervisors.  
30  
31

#### 32 33 SAFETY & TRUST

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35  
36 In order to connect to helpers, it was essential for people to feel safe in those  
37  
38 relationships and able to trust that the person would be a helper and not a barrier to healing.  
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42 Persons whose wounds included a violation of trust were especially careful about testing  
43  
44 the safety of new relationships. One survivor of incest tested the boundaries of relationships to  
45  
46 make sure they were safe. She said, *“I always felt like I pushed boundaries but I needed them*  
47  
48 *really badly. I needed to make sure nobody was going to violate them, but I needed first to know*  
49  
50 *where they are and I needed to figure out if they were comfortable.”* (participant 1)  
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3 When safety and trust had been established, people were able to connect with helpers.  
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5 The nature of the behaviors of helpers that fostered healing ranged from small acts of kindness to  
6  
7 unconditional love. Some illustrative quotations are included below.  
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9

10  
11 A grandmother: *“She was a very good nurturer matriarch who sort of on the outside you*  
12  
13 *couldn’t tell she was the matriarch. But she really was. She was running everything. And she*  
14  
15 *was just so unconditional positive love for me and all my cousins”*(participant 1)  
16  
17

18  
19 Dogs: *“It’s one of the most important things that I’ve ever felt. It’s like a love that the*  
20  
21 *animal shows. And you can get that from people too, but not near as often.”*(participant 2)  
22  
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24  
25 God: *“I heard God talk to me. I felt his presence. And I think that’s what keeps me in*  
26  
27 *recovery”*(participant 3)  
28

29  
30 Office venipuncturist: *“Anytime I have to give blood ...any place else it’s like, “They’re*  
31  
32 *going to see my track marks and they’re going to say, ‘Oh, my God!’ like you’re being judged.*  
33  
34 *But I don’t feel that here. I have a good relationship with the venipuncturist too, the lady that*  
35  
36 *draws the blood. She says “Oh, you have such good veins now.” So they’re so accepting and*  
37  
38 *they’re so happy for you that you are doing well.”*(participant 3)  
39  
40

41  
42 Support group: *“we had 40 participants on a weekend, plus the team people...like 50*  
43  
44 *people every single time. And incredible healing to be able to say this and to have these people*  
45  
46 *accept me and love me and care about me.”*(Participant 4)  
47  
48

49  
50 Physician: *“I went from the darkest despair to bright hope. And that was because of him*  
51  
52 *and what he said to me and how he said it and just the caringness of him.”*(participant 5)  
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3 One person found another way to connect outside himself. He found healing in creating art.  
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5 He said, *“When I’m either taking pictures with my camera, framing them, painting and*  
6  
7 *sculpturing, that’s my best. That’s the best healer for me.” (participant 6)*  
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9

#### 10 11 ACQUIRING RESOURCES AND SKILLS 12

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14 Making connections enabled subjects to acquire and refine resources and skills that were  
15  
16 essential in their healing journey. People also brought their own personal strengths to the  
17  
18 journey.  
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21 A particularly important skill was ***the ability to reframe*** - that is to look at suffering  
22  
23 through a different lens. One person, who was struggling with her history of sexual abuse by  
24  
25 family members, said of her therapist, *“I think I kept trying to convince him I was crazy. And he*  
26  
27 *kept saying, “No you’re not crazy.” He didn’t pathologise, a lot of things he saw as a reaction*  
28  
29 *to some atrocious circumstances, rather than like the way you wouldn’t necessarily say a*  
30  
31 *Vietnam Vet was crazy. You’d say they are responding like you’d expect to extraordinary*  
32  
33 *circumstances.”(participant 1)* This person learned this skill from her therapist, and then was  
34  
35 able to use it herself. She said, *“And I think the meaning I was holding onto was ...not that this*  
36  
37 *happened because, but maybe a way to sort of put a positive spin on something that you can’t*  
38  
39 *ever imagine to put a positive spin on would be for me to help other survivors and that would...I*  
40  
41 *almost started feeling stronger, like having this experience and survived it made me better than I*  
42  
43 *would have been otherwise”(participant 1)*  
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51 Another subject who had HIV infection said, *“I’m not the only one who have this*  
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53 *problem. A lots, millions of people, you know. Little babies, little kids. They don’t have nothing*  
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3 *to do with that. They have it, you know. I guess I have to live. And that was one of the things*  
4 *that used to keep me real stable.”(participant 7)*  
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8  
9 Another resource that people acquired or refined during their healing journey was **to**  
10 **choose to be positive** – that is to have some optimism about their situation. For some, being  
11 positive was a trait they already had. For example, one person said, *“Yes, you have to be positive.*  
12 *And like I said, it’s everything. I’m very positive. Honestly, I’m a very positive*  
13 *lady.”(participant 8)*  
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21 Some people, however, learned to choose to be positive through their helping connections.  
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23 The person quoted above with HIV infection was in despair and ready to die, but by connecting  
24 to his sister he was able to change his attitude. He said, *“I always not even thinking negative,*  
25 *You always gotta think positive. You always gotta think how beautiful life is.”(participant 7)*  
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31 A third essential resource that people acquired or refined was the ability **to take an**  
32 **appropriate amount of responsibility** for their healing journeys. They participated actively in  
33 the process of healing. Once again, some subjects already had developed this skill, and some  
34 acquired or refined it from their helpers. One subject described the degree of participation  
35 required: *“You need a lot of energy and a lot of work...it takes a lot of work. It doesn’t just*  
36 *happen. It’s not like a magic wand. “I’ll go to the right doctor and boom.”(participant 9)*  
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45 Another person said, *“I have to contribute just as much as every therapist and then some,*  
46 *because I have to do it for myself. And if I’m not helping myself who the heck should? I’d better*  
47 *take care of myself and I’ve got to try and discern when something is necessary to be tended to*  
48 *or when something is not necessary to be tended to and know to differentiate the*  
49 *two.”(participant 10)*  
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3 Some people needed help in taking an appropriate amount of responsibility. For example,  
4 one person was lost in the depths of substance abuse. She was taking so many pills that she went  
5 to sleep in the middle of a conversation in which she was asking for more pills from the  
6 psychiatrist at the methadone clinic. She describes what happened then: *“So, when I woke up...  
7 all the administrators from the program were in the office. And they said, “If you don’t get help,  
8 we’re kicking you off the clinic.” So, they said, “You have a week.” And they found me a place  
9 and I went through detox off the pills. And when I got off the pills, because I was so clouded  
10 up...when I got off the pills, it was like a rebirth. And I sort of had like a spiritual awakening  
11 and stuff came to me...and ever since then...I still struggled a little bit, but I started getting  
12 dedicated, I started making meetings.”(participant 3)*  
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#### 28 EMERGENT CHARACTERISTICS

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31 **Persistence** –People did not simply progress through this sequence and experience  
32 healing. The healing journey was a recursive, back and forth process. They found helpers,  
33 utilized the skills/resources that those helpers provided, found other helpers that provided more  
34 resources and utilized those skills and resources. As this process continued, people experienced  
35 a gradual amelioration of their suffering. Although many despaired at times, all demonstrated  
36 the quality of persistence – they refused to give up. One subject said, *“And when I couldn’t see  
37 the light on the other side, I still struggled every day to live. I still struggled every day to  
38 live.”(participant 3)*  
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50 As people struggled through their recursive healing journeys, several common  
51 characteristics began to emerge, which we document here with illustrative quotations:  
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**Hope** – the expectation that there can be an end to present suffering. *“I think gradually I realized that I was going to feel better. I did have days when I actually didn’t vomit, when I did feel better. And I think gradually I came to believe that maybe I could have a normal life again.”(participant 11)*

**Self – Acceptance** – the ability to accept oneself as a valuable person *“I’m really proud of myself. I think that now I still want to live. I don’t want to die, and I really love myself a lot. I have a lot of comfort in myself.”(participant 7)*

**Desire to help others** – understanding that suffering gives the strength and experience to help others in similar situations. *“So, I think that’s what helped me plug along. I just don’t feel like... I always feel like I have to feel that I can do something for somebody else, not just always done for me. I didn’t want to feel just passive; I could be doing something for somebody else too.”(participant 12)*

**Healing** – the re-establishment of a sense of integrity and wholeness. We found we could best understand healing as an emergent property of the complex healing journeys of individuals in the context of their lives. None of these people were cured of their illnesses, but all developed a sense of integrity and wholeness despite ongoing pain or other symptoms. To one degree or another they were all able to transcend their suffering and in some sense to flourish:

*“I think the gradual realization through my stress class and everything was the acceptance of the fact that it wasn’t going to go away. It did not go away, but it did not have to mean the end of my life in terms of never being able to do anything I enjoyed ever again, or being able to eat anything I enjoyed ever again.”(participant 11)*



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3                   *" Yeah, and it's just like just connections, like the healing process is about like*  
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5                   *connecting to other people, like you're not by yourself in this world. ...So, it's like we're so*  
6  
7                   *attached; yet we're so disconnected. And I think that that's the mission is for connectedness, for*  
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9                   *wholeness."*(participant 3)  
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## 12 13 14 Model

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16                   From these themes we developed a **model**, illustrated in Figure 1. Moving clockwise  
17  
18 from the upper left, the model shows that an initial physical/emotional wounding leads to  
19  
20 suffering. The manifestation and degree to which the initial wound causes suffering is dependent  
21  
22 on people's personal characteristics, relationships, and stage in the developmental life course.  
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26                   People's healing journey is facilitated by persistence, and through developing a sense of  
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28 safety and trust. This allows the person to make new connections to relationships with helping  
29  
30 others and to acquire important resources, such as reframing, responsibility, and positivity.  
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32 Bridges develop between the various connections made, and resources that are acquired. Over  
33  
34 time, these relationships and resources foster hope, self-acceptance and the desire to help others,  
35  
36 leading, in fits and starts, to the emergence of a sense of wholeness and integrity that constitutes  
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38 healing.  
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## 46 **Discussion**

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48                   This study has demonstrated that the path to healing is not a simple, linear process, but  
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50 rather, a complex journey that involves suffering, connecting with others, and acquiring needed  
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52 resources. The journey requires persistence and the ability to find trustworthy relationships with  
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54 others. As this recursive process continues, emergent personal properties of hope, self-  
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3 acceptance, and helping others develop. Gradually a sense of integrity and wholeness develops  
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6 despite continuing symptoms of the original insult or illness.  
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9 Most of the literature on healing focuses on relationships between health care  
10  
11 professionals and their patients. This is exemplified by Jackson in the nursing literature.<sup>10,28</sup>  
12  
13 Egnew developed his definition of healing by analyzing interviews with physicians<sup>7</sup> and Hsu, et  
14  
15 al developed their definition of healing in focus groups with physicians, nurses, clinical staff and  
16  
17 patients.<sup>6</sup> Churchill, et al interviewed patients, but their focus was on qualities of physicians that  
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19 patients felt contributed to their healing.<sup>14</sup> In contrast to much of this literature, our study focuses  
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21 on how people experience the progression from illness and suffering to healing. Relationships  
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23 with health care professionals were a part of that process but often not the most important part.  
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28 Recently, psychiatry has put emphasis on the need for recovery, even if the disease is not  
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30 cured, within their 'recovery movement'<sup>29</sup> and one recent review suggested that the key  
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32 processes involved were connectedness, hope and optimism, identity, finding meaning, and  
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34 empowerment.<sup>30</sup> Again, this is in accord with our findings.  
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38 This study expands on the previous work of Scott et al,<sup>8</sup> which focused on the nature of  
39  
40 the healing relationship between physicians and their patients, but noted that other kinds of  
41  
42 relationships facilitated healing. The present study is unusual, as we have focused on the  
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44 experiences of 'patients' rather than professionals - a group of people on the slow journey from  
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46 illness and suffering to healing. Relationships with health care professionals were important, but  
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48 were only part of the process. Connections within and beyond the self, and relationships with  
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50 other people, animals or creativity, were similarly important.  
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55 Acquiring new resources and skills is something that is stressed by the recovery  
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57 movement, which tries to empower people to find the resources they need.<sup>29,30</sup> The narratives  
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3 that we analyzed suggest that in conventional, disease-orientated, primary and secondary care  
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5 settings, people had to find their own way towards both acquiring the necessary skills and  
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7 resources, and to making meaning of their problems. They had to accept responsibility for  
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9 themselves, reframe their experiences and choose positivity in order to make progress towards  
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11 healing.  
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15 Only when they had made some appropriate connections, acquired necessary skills, and  
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17 persevered, could healing emerge, along with hope, self-acceptance and a desire to help others.  
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19 Even then, our informants often described continued suffering, but they were now able to  
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21 function effectively: the key outcome of healing processes in the view of Cassel.<sup>2</sup> This concept  
22  
23 is also in accord with the Aristotelian ideas of flourishing and eudaimonia – the idea that we  
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25 should all live life to fulfill our capabilities (which vary according to constitution and illness), for  
26  
27 the sake of the whole community as well as ourselves.<sup>31</sup> Research on patients with chronic  
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29 illness has shown that this concept remains relevant to their ability to function well.<sup>32</sup>  
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35 There are limitations to our analysis. The patients in this study were purposefully chosen  
36  
37 by their physicians as likely to have experienced healing, and, as such, are likely to not be  
38  
39 representative of ill people in general – they were purposefully selected to have rich and deep  
40  
41 experience of the phenomena we were trying to elucidate. The resulting model, therefore, is  
42  
43 relevant to bringing hope to people who are suffering — hope that healing is possible. The  
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45 model also brings a sufficiently detailed description of the healing process that it may be useful  
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47 to individuals struggling to heal, or to people attempting to help them through the healing  
48  
49 journey. We do not presume, however, that healing always happens or is even always possible.  
50  
51 It is not our intention to contribute to a “cult of positivity”<sup>33</sup> to disparage those who have not  
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53 experienced a healing journey as we have described it. It is possible that the path to healing is  
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3 affected by sex, race, ethnicity, and a host of other factors that were not apparent in our small  
4 sample. Thus, our findings cannot be used to generalize about the effects of demography, time,  
5 place or culture. Although the interviews for this study were conducted ten years ago, it is  
6 unlikely that the experience of illness, suffering and healing is any different today than it was  
7 then. Interview data have the inherent limitation of dealing with perceptions of respondents'  
8 experiences of events rather than observations of events themselves, but in this study the  
9 perceptions of respondents was exactly what we wanted to capture and individual interviews  
10 were a reasonable approach. Our analysis uses an interpretivist paradigm.<sup>34</sup> Researchers who  
11 adhere to other qualitative research paradigms, particularly the positivist paradigm may find fault  
12 with our analysis approach. Our interpretation of these data is inevitably influenced by our life  
13 experience. Others might view the data differently and come to different conclusions. The  
14 validity of our analysis, however, is enhanced by the training and experience of the analysis  
15 team, reflexivity (reflecting on our own experiences), and searching the data for disconfirming  
16 evidence after we identified themes.

17  
18 The findings of our study, which describes the journey of healing may give hope to people  
19 suffering from illness and may suggest some strategies for them to use to begin their own healing  
20 journey. Programs designed to serve patients may use the findings to align their offerings and  
21 staff training with these stages of the healing journey. Health professionals should look at these  
22 findings not as minimizing their role in helping to facilitate healing, but rather putting that role in  
23 the larger context of their patients' healing journey. Understanding the pathways from wounding  
24 and suffering to the emergence of healing can inform and encourage individuals' healing journey,  
25 and may help others to be supportive of their fellow travelers in fostering healing.

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He coordinated and participated in the conference calls for data analysis. He was present for and participated in the two-day retreat for final data analysis. He wrote the first draft of the paper and contributed to all subsequent drafts including the final one. Sara Warber participated in the data analysis via conference calls and was present at the two-day retreat for final data analysis. She added her input to multiple drafts of the paper and she prepared the final figure of the healing journey model. Paul Dieppe participated in the data analysis via conference calls and was present at the two-day retreat for final data analysis. He added his input to multiple drafts of the paper and wrote the initial draft of the introduction section. Kurt Stange participated in the data analysis via conference calls and was present at the two-day retreat for final data analysis. He added his input to multiple drafts of the paper and wrote the initial draft of the abstract. David Jones participated in the data analysis via conference calls and was present at the two-day retreat for final data analysis. He added his input to multiple drafts of the paper and was instrumental in helping to refine the healing journey model. All authors gave final approval of this version and all agree to be accountable for all aspects of the work.

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8 American Cancer Society.  
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10  
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14

15  
16 **Data Sharing Statement:** The de-identified interview transcripts are available from the  
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18 corresponding author upon request.  
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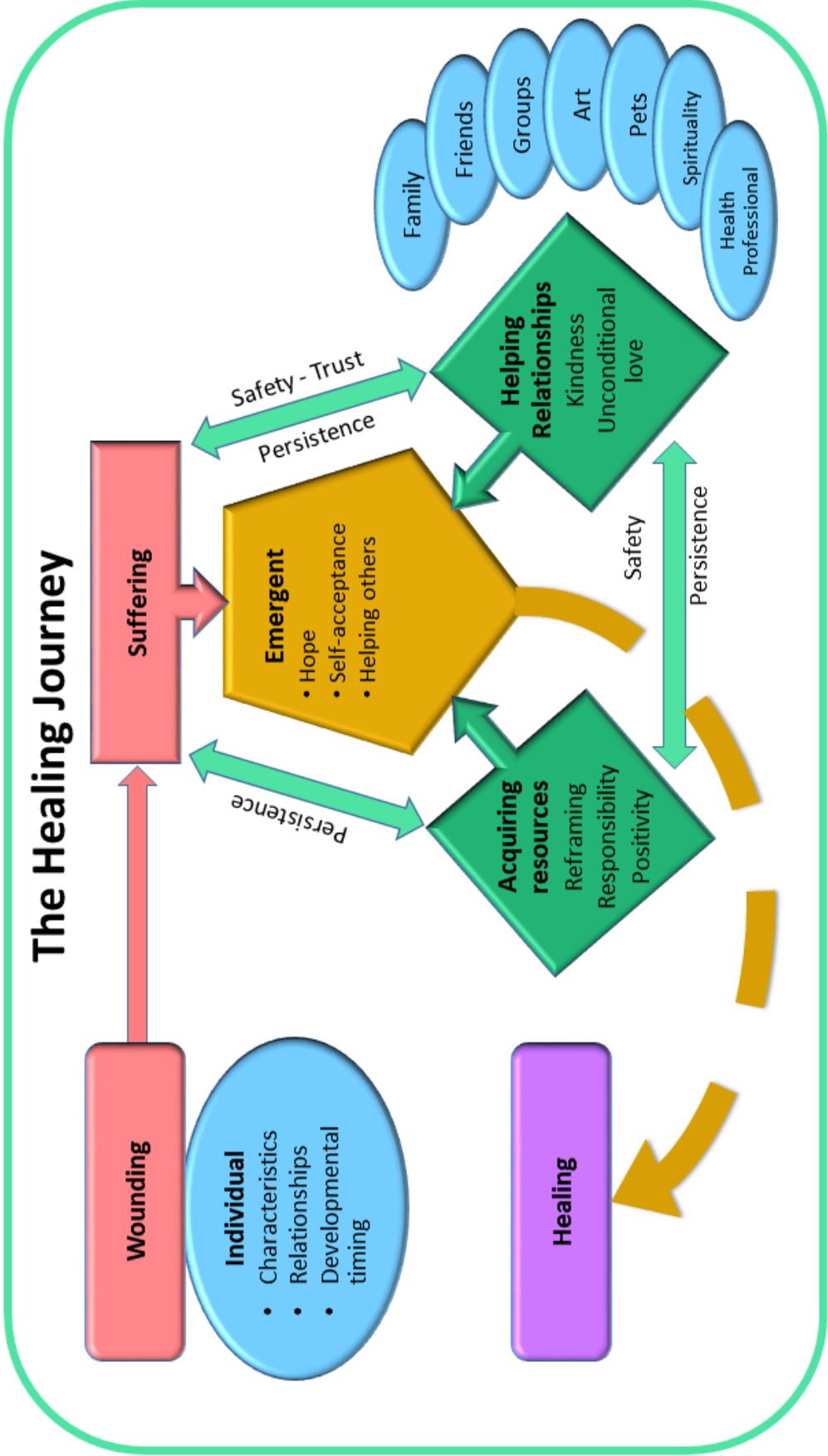
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## Qualitative Analysis COREQ Checklist

| No   | Item   | Guide questions/description   |
|--|--|---|
| <b>Domain 1:<br/>Research team<br/>and reflexivity</b> |  |   |
| Personal<br>Characteristics                            |  |   |
| 1.   | Interviewer/facilitator                        | <i>The corresponding author, JGS, conducted the Interviews Page 5</i>   |
| 2.   | Credentials                                    | JGS: MD, PhD<br>SLW: MD<br>PD: MD, FRCP, FFPH<br>DJ: MD<br>KCS: MD, PhD   |
| 3.   | Occupation                                     | JGS: practicing physician<br>SLW: Teaching and research<br>University of Michigan<br>PD: Faculty researcher University of<br>Exeter Medical<br>School<br>DJ: Director Emeritus Institute for<br>Functional Medicine<br>KCS: Faculty and full time researcher<br>Case Western<br>Reserve University. |
| 4.   | Gender   | JGS: Male<br>SLW: Female<br>PD: Male<br>DJ: Male<br>KCS: Male   |
| 5.   | Experience and<br>training                     | JGS: Fellowship Robert Wood<br>Johnson Medical School<br>focusing on qualitative research.<br>Author on multiple<br>qualitative research papers   |
| Relationship<br>with participants                      |  |   |
| 6.   | Relationship<br>established                    | There was no established relationship<br>with the subjects<br>prior to the interviews   |
| 7.   | Participant<br>knowledge of the<br>interviewer | Participants knew the interviewer was<br>a physician<br>interested in how they had<br>experienced healing   |
| 8.   | Interviewer                                    | Reported in original paper. Family  |

|                                   |                                       |   |
|-----------------------------------|---------------------------------------|---|
|                                   | characteristics                       | physician with interest in how healing relationships develop. Biases were reported as well as how biases were managed (Scott, et al. Understanding healing relationships in primary care. <i>Ann Fam Med.</i> Jul-Aug 2008;6(4):315-322. Pages 315-316) |
| <b>Domain 2:<br/>study design</b> |                                       |   |
| Theoretical framework             |                                       |   |
| 9.                                | Methodological orientation and Theory | Grounded Theory with Immersion-Crystallization (Page 7)   |
| Participant selection             |                                       |   |
| 10.                               | Sampling                              | Purposive sampling (Page 6)   |
| 11.                               | Method of approach                    | Contacted by their primary care physician and those agreeing to participate contacted by telephone. (Page 6)  |
| 12.                               | Sample size                           | 23 (Page 8)   |
| 13.                               | Non-participation                     | 0   |
| Setting                           |                                       |   |
| 14.                               | Setting of data collection            | Participants chose where to be interviewed. Some at home, some in doctor's office, some in local restaurants, etc. (Page 6)   |
| 15.                               | Presence of non-participants          | No one other than the interviewer and the participants were present. (Page 6)   |
| 16.                               | Description of sample                 | Ages ranged from 30-86 at the time of interview (mean 58); 14 were female and 9 male; 17 were White, 4 Hispanic and 2 Black; 14 were of high socioeconomic status, 4 mid and 5 low. (Page 8)  |
| Data collection                   |                                       |   |
| 17.                               | Interview guide                       | A semi-structured interview guide was used. It was tested on pilot interviews and modified after analysis of those interviews (Page 6)  |
| 18.                               | Repeat interviews                     | There were no repeat interviews   |

|   |                                |  |
|---|--------------------------------|--|
| 19.                                     | Audio/visual recording         | Interviews were recorded on a small digital audio recorder (Page 6)  |
| 20.                                     | Field notes                    | Field notes were made during and after each interview (Scott, et al. Understanding healing relationships in primary care. <i>Ann Fam Med.</i> Jul-Aug 2008;6(4):315-322 Page 316)                |
| 21.                                     | Duration                       | Interviews lasted 1-3 hours (Page 6)   |
| 22.                                     | Data saturation                | Interviews were analyzed iteratively and data saturation was reached (Scott, et al. Understanding healing relationships in primary care. <i>Ann Fam Med.</i> Jul-Aug 2008;6(4):315-322 Page 317) |
| 23.                                     | Transcripts returned           | Transcripts were not returned to the participants  |
| <b>Domain 3: analysis and findingsz</b> |                                |  |
| Data analysis                           |                                |  |
| 24.                                     | Number of data coders          | All authors participated in data coding. (Pag 7)   |
| 25.                                     | Description of the coding tree | Codes were used simply as descriptors of interesting pieces of text. There was no formal hierarchical coding tree. (Page 7)  |
| 26.                                     | Derivation of themes           | Themes were derived from the data. (Pages 9-14)  |
| 27.                                     | Software                       | Atlas ti qualitative analysis software (Page 6)  |
| 28.                                     | Participant checking           | Data was de-identified for this analysis, so participant checking was not possible. (Page 6)   |
| Reporting                               |                                |  |
| 29.                                     | Quotations presented           | Participant quotations were used and identified by participant number (Pages 9-14)   |
| 30.                                     | Data and findings consistent   | The findings were derived directly from the data and were consistent. (pages 9-14)   |
| 31.                                     | Clarity of major themes        | Major themes were clearly presented in the findings. (Pages 9-14)  |
| 32.                                     | Clarity of minor themes        | Analysis included a search for disconfirming data. There was only one minor theme. Page 10,  |

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For peer review only

# BMJ Open

## The healing journey: a qualitative analysis of the healing experiences of Americans suffering from trauma & illness

|                                    |   |
|------------------------------------|---|
| Journal:                           | <i>BMJ Open</i>   |
| Manuscript ID                      | bmjopen-2017-016771.R1  |
| Article Type:                      | Research  |
| Date Submitted by the Author:      | 10-Jun-2017   |
| Complete List of Authors:          | Scott, John; Northeastern Vermont Regional Hospital, Corner Medical<br>Warber, Sara; University of Michigan Medical School, Family Medicine<br>Dieppe, Paul; University of Exeter Medical School, Institute of Health<br>Research<br>Jones, David; Institute for Functional Medicine<br>Stange, Kurt; Case Western Reserve University School of Medicine, Family<br>Medicine and Community Health |
| <b>Primary Subject<br>Heading</b>: | Qualitative research  |
| Secondary Subject Heading:         | Patient-centred medicine, General practice / Family practice  |
| Keywords:                          | MENTAL HEALTH, PRIMARY CARE, SOCIAL MEDICINE  |
|                                    |   |

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# The healing journey: a qualitative analysis of the healing experiences of Americans suffering from trauma & illness.

John G. Scott, MD, PhD<sup>1,6</sup>

Sara L. Warber MD<sup>2,3</sup>

Paul Dieppe, MD, FRCP, FFPH<sup>3</sup>

David Jones, MD<sup>4</sup>

Kurt C. Stange, MD, PhD<sup>5</sup>

1 Northeastern Vermont Regional Hospital, Corner Medical, 195 Industrial Parkway Box 53, Lyndonville, Vermont 05851. Email: [john.glen.scott@gmail.com](mailto:john.glen.scott@gmail.com). Telephone: 802-748-9501-Ext 225 Fax: 802-748-3420

2 Department of Family Medicine, University of Michigan Medical School, Ann Arbor, Michigan

3 University of Exeter Medical School, Exeter, UK

4 The Institute for Functional Medicine

5 Departments of Family Medicine & Community Health, Epidemiology & Biostatistics, and Sociology; Case Comprehensive Cancer Center, Cleveland Clinical & Translational Science Collaborative, Case Western Reserve University, Cleveland, Ohio

6 Department of Community and Family Medicine, Dartmouth Geisel School of Medicine, Hanover, New Hampshire

Word count: Abstract: 229; Text (including quotations): 5607

Tables: none

Figures: 1

## Abstract

**Objectives:** To elucidate pathways to healing for people having suffered injury to the integrity of their function as a human being.

**Methods:** A team of physician-analysts conducted thematic analyses of in-depth interviews of 23 patients who experienced healing, as identified by six primary care physicians purposefully selected as exemplary healers.

**Results:** People in the sample experienced healing journeys that spanned a spectrum from overcoming unspeakable trauma and then becoming healers themselves, to everyday heroes functioning well despite ongoing serious health challenges.

The degree and quality of suffering experienced by each individual is framed by contextual factors that include personal characteristics, timing of their initial or ongoing wounding in the developmental life cycle, and prior and current relationships.

In the healing journey, bridges from suffering are developed to healing resources/skills and connections to helpers outside themselves. These bridges often evolve in fits and starts, and involve persistence and developing a sense of safety and trust.

From the iteration between suffering and developing resources and connections, a new state emerges that involves hope, self-acceptance, and helping others. Over time this leads to healing that includes a sense of integrity and flourishing in the pursuit of meaningful goals and purpose.

**Conclusion:** Moving from being wounded, through suffering to healing, is possible. It is facilitated by developing safe, trusting relationships, and by positive reframing that moves through the weight of responsibility to the ability to respond.

## Strengths and limitations of this study

### Strengths

- This is one of few studies to examine healing from the patient perspective
- Participants were selected to maximize probability that they have experienced healing
- Data consist of rich in-depth interviews with participants
- Qualitative analysis done by a diverse team
- The validity of our analysis is enhanced by the training and experience of the analysis team, reflexivity (reflecting on our own experiences), and searching the data for disconfirming evidence after we identified themes.
- Analysis used to generate a theoretical model of how patients experience healing
- This model may give guidance and hope to people experiencing illness and suffering
- The model may help clinicians understand their limited but important role in patients' healing journeys.

### Limitations

- Because participants were selected for their experience of healing, they are likely to not be representative of ill people in general
- We do not presume that healing always happens or is even always possible
- It is possible that the path to healing is affected by sex, race, ethnicity, and a host of other factors that were not apparent in our small sample. Thus, our findings cannot be used to generalize about the effects of demography, time, place or culture.
- Our interpretation of these data is inevitably influenced by our life experience.

## Introduction

As medicine moves away from the Cartesian reductionism that considers patients as collections of organ systems and deposits of diseases,<sup>1</sup> there has been much interest in how medical professionals can foster healing.<sup>2</sup> The word “healing” comes from the Old English *haelan* meaning “whole” and alludes to a process that brings wholeness in physical, emotional, intellectual, social, and spiritual aspects of self.<sup>3</sup> There are several definitions of healing in the medical literature. Csordas describes healing as a transformational change.<sup>4</sup> Egnew talks of transcending suffering.<sup>6</sup> Kirmayer describes it as a journey from feeling ill to wellness.<sup>5</sup> Hsu and colleagues<sup>6</sup> emphasize recovery and regaining a sense of balance and peace. Cassel defines healing as “making whole again.”<sup>2,7</sup> Scott et al describe it as being cured when possible, reducing suffering when cure is not possible, and finding meaning beyond the illness experience.<sup>8</sup> All of these definitions have in common the idea of recovering a sense of integrity and wholeness after experiencing illness and suffering. This synthesis is the definition of healing that we used in our analysis.

In 2001 the Institute of Medicine included the “development of continuous healing relationships” as their first priority in improving the quality of medicine.<sup>9</sup> The nursing literature has been particularly important in theoretical development and empirical studies related to nurse-patient relationships, especially with regards to caring.<sup>10,11</sup> Studies on healing relationships between doctors and patients have focused on interviews with physicians<sup>7,12,13</sup> or patients<sup>14</sup> or both.<sup>6,8</sup> While this focus on healing relationships between health professionals and patients is useful for health professionals, what is missing from this literature is a description of the experience of people who are ill and how they manage to find healing. Eric Cassels describes the dilemma we continue to face: “...from all this, we would have to conclude that it is not known

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3 what the basis of healing is, BUT also there is little doubt that there really is something called  
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5 healing.”<sup>2</sup>  
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9 Although there is a literature on patients’ experience of healing, it consists primarily of  
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11 anecdotal reports (pathographies) by individuals describing their personal experiences with  
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13 illness and healing.<sup>15</sup> There are a few systematic qualitative studies of healing from the patient  
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15 perspective in the nursing literature, but all of these describe healing from specific illnesses.<sup>16-20</sup>  
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17 Verhoef and Mulkins did a qualitative analysis of the healing experiences of patients with a  
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19 diversity of diseases, but this was limited to patients attending integrative clinics that included  
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21 complementary and alternative practitioners.<sup>21</sup>  
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26 Because of a continued need for deeper understanding of the process of healing from the  
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28 point of view of the person experiencing it, this study was undertaken to explore pathways to  
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30 healing for people who have been wounded by serious illness and/or life events and who access  
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32 care through the conventional health system.  
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## 38 **Methods**

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41 We conducted a qualitative analysis of transcripts of in-depth interviews with 23 people  
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43 who had experienced healing. This was a secondary analysis of data originally collected by  
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45 Scott, et al in their study of healing relationships between doctors and patients.<sup>8</sup> That study  
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47 included physician interviews as well and focused on how doctors and patients experienced their  
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49 relationships with each other. In this study we used only the patient interviews, which contained  
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51 rich descriptions of pathways to healing.  
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## 56 Sampling Strategy

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3 As described in more detail by Scott et al,<sup>8</sup> physicians believed to be exemplars in  
4 developing and maintaining healing relationships were purposefully selected based on an  
5 assessment of publications, such as books about patient relationships), reputation by peer  
6 nomination, and awards such as Family Doctor of the Year. Each physician was interviewed and  
7 also asked to identify 3-6 adult patients whom they perceived to have experienced healing.  
8 These patients were contacted personally by the physician and asked if they were willing to take  
9 part; they constitute the sample for the current study. This sampling strategy was designed to  
10 maximize the probability of finding the phenomenon we wished to study; that is people who had  
11 experienced healing. One physician did not contact any of his patients. This was the only refusal  
12 in the study. The interviewer had no relationship with any of the participants with the exception  
13 of five patients from his previous practice.  
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### 30 Interviews

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33 Participants were contacted by telephone or email to schedule interviews. At the  
34 interview meeting participants were informed that the researcher was a physician and that the  
35 purpose of the research was to study healing. After obtaining written informed consent, the first  
36 author conducted face-to-face in-depth interviews, alone with the participants according to a  
37 semi-structured interview guide\* that contained several grand tour questions<sup>22</sup> designed to elicit  
38 healing stories from the participants. The interview guide included questions about healers other  
39 than physicians as well as questions about what patients bring to healing relationships. Because  
40 the interviews were analyzed iteratively, the interview guide underwent modifications through  
41 the first few interviews. Interviews lasted 1 to 3 hours, and were conducted at places of the  
42 participants choosing, most commonly in their homes, but some at their physician's office and  
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58 \* See [http://www.annfammed.org/content/suppl/2008/07/07/6.4.315.DC1/Scott\\_App\\_1-2.pdf](http://www.annfammed.org/content/suppl/2008/07/07/6.4.315.DC1/Scott_App_1-2.pdf)  
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3 some at restaurants or other venues chosen by the participants. There were no repeat interviews.  
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5 The interviews were recorded and transcribed. The interviewer also recorded field notes after  
6  
7 each interview. Transcripts were checked for accuracy and were imported into qualitative  
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9 analysis software, Atlas-ti.<sup>23</sup> Because of logistical difficulties it was not possible to return the  
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11 transcripts to the participants for comment and correction. The Robert Wood Johnson Medical  
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13 School Institutional Review Board approved the original study,<sup>8</sup> and determined that further  
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15 research using de-identified transcripts would not require institutional review board review.  
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21 A total of 23 participants, identified by their physicians as people who had experienced  
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23 healing, were interviewed. Their ages ranged from 30-86 at the time of interview (mean 58); 14  
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25 were female and 9 male; 17 were White, 4 Hispanic and 2 Black; 14 were of high socioeconomic  
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27 status, 4 mid and 5 low.  
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31 Participants had a complex mixture of medical, psychological and social issues, which  
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33 included: myocardial infarction, congestive cardiac failure, inflammatory bowel disease, cancer,  
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35 diabetes, chronic pain, HIV infection, substance abuse, obsessive-compulsive disorder, incest  
36  
37 and sexual abuse. Most of the interviewees had more than one problem.  
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#### 40 41 Analysis 42

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44 The current analysis team consisted of a family physician with 21 years' experience in  
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46 private practice as well as extensive experience in qualitative research and analysis (JGS), two  
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48 practicing family physicians from large academic medical centers, both of whom have  
49  
50 qualitative research experience (KCS) and (SLW), a rheumatologist/health services researcher  
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52 from an academic medical center in the United Kingdom who is undertaking research on healing  
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54 (PD), and a practicing family physician from the west coast of the U.S. who was instrumental in  
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3 developing the concepts, knowledge base and tools for the clinical application of functional  
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5 medicine<sup>24</sup> (DJ).  
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9 Analysis proceeded iteratively,<sup>22</sup> using a combination of editing<sup>25</sup> and  
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11 immersion/crystallization<sup>22</sup> approaches. These qualitative methods are a modification of a  
12  
13 grounded theory approach to analysis<sup>26</sup> that has been well documented by Crabtree and Miller.<sup>27</sup>  
14  
15 Initial preliminary coding was done by the first author. Over several months, the analysis team  
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17 individually read the interviews. The interviews were then discussed as a group via a number of  
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19 conference calls. One member served as primary analyst for each interview, producing an initial  
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21 summary and thematic analysis supported by representative quotations, and refining this case  
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23 analysis as the group discussion produced confirming or disconfirming data and additional  
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25 interpretations.  
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30 Case studies were analyzed to identify common themes. Finally, at a three-day intensive  
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32 retreat, the analysis team extensively discussed these themes, referring back to the original data  
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34 and case summaries for confirming and disconfirming evidence. This analysis was used to  
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36 develop a model of pathways to healing. The data were de-identified, so we were unable to have  
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38 participants comment on the analysis.  
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#### 42 43 Data Saturation 44

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46 Interviews were analyzed iteratively by the original research team.<sup>8</sup> Interviews continued  
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48 until the team found no more new themes emerging from the interviews. At that point the team  
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50 determined that data saturation had been reached and the interviews were terminated.  
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## Findings

### The healing journeys

Analyses revealed that healing was not an isolated event that happened at a particular point in time. Rather, healing typically took place in fits and starts over an extended period of time. This process was not linear and not predictable. The path to healing was different for each person. The metaphor of a journey emerged as an apt description of this process, because that was how the participants talked about their experiences of healing. These journeys spanned a spectrum from overcoming unspeakable trauma (sexual abuse by a parent for example) and then becoming healers themselves (therapist, social worker for example), to everyday heroes functioning despite ongoing health challenges (for example – functioning in family and daily life despite enduring chronic pain from inflammatory bowel disease). During their journeys all the participants experienced suffering, defined as the experience of distress when the intactness or integrity of the person is threatened.<sup>2</sup>

### Major Themes that Describe the Healing Journey

#### CONNECTIONS OUTSIDE ONESELF

Connection to others was an essential part of all the healing journeys. As participant P1.1 who had severe depression and an eating disorder, said, *“Once I started connecting with people, I started healing.”* This connection was with other patients while she was hospitalized.

People experiencing healing developed relationships with many kinds of helpers. Relationships with health professionals were among these, but were not necessarily any more important to the healing journey than other kinds of helpers, which included family members,

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3 friends, spirituality and their God, pets, support groups, administrators, case workers and  
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5 supervisors.  
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## 8 9 SAFETY & TRUST 10

11 In order to connect to helpers, it was essential for people to feel safe in those  
12 relationships and able to trust that the person would be a helper and not a barrier to healing.  
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17 Persons whose wounds included a violation of trust were especially careful about testing  
18 the safety of new relationships. Participant E3.4, a survivor of incest tested the boundaries of  
19 relationships to make sure they were safe. She said, *“I always felt like I pushed boundaries but I*  
20 *needed them really badly. I needed to make sure nobody was going to violate them, but I*  
21 *needed first to know where they are and I needed to figure out if they were comfortable.”* When  
22 safety and trust had been established, people were able to connect with helpers.  
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32 The nature of the behaviors of helpers that fostered healing ranged from small acts of  
33 kindness to unconditional love.  
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37 Participant E3.4 was abused by her father and uncle, but found unconditional love from  
38 her maternal grandmother: *“She was a very good nurturer matriarch who sort of on the outside*  
39 *you couldn’t tell she was the matriarch. But she really was. She was running everything. And*  
40 *she was just so unconditional positive love for me and all my cousins.* The love from her  
41 grandmother helped mitigate the pain of the abuse at home.  
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49 Participant J.4 was socially isolated from people partly because he was ashamed of his  
50 HIV infection. He received unconditional love, however, from his dogs: *“It’s one of the most*  
51 *important things that I’ve ever felt. It’s like a love that the animal shows. And you can get that*  
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3 *from people too, but not near as often.*” The love he felt from his dogs helped him cope with his  
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5 social isolation and depression.  
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9 Participant, P2.3 in the depths of drug abuse and HIV infection, had a transformative  
10 religious experience. *“I heard God talk to me. I felt his presence. And I think that’s what keeps*  
11 *me in recovery”* Participant P2.3 was also grateful for small acts of kindness. She related this  
12  
13 story about the office venipuncturist: *“Anytime I have to give blood ...any place else it’s like,*  
14 *“They’re going to see my track marks and they’re going to say, ‘Oh, my God!’ like you’re being*  
15 *judged. But I don’t feel that here. I have a good relationship with the venipuncturist too, the*  
16 *lady that draws the blood. She says “Oh, you have such good veins now.” So they’re so*  
17 *accepting and they’re so happy for you that you are doing well.”* This is an example of the  
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19 importance of compassion in every interaction with people in the health care system.  
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30 Participant E4.3 experienced sexual abuse as a child and ended up in a bad marriage as  
31 well. She participated in a support group in which she experienced love and healing: *“we had 40*  
32 *participants on a weekend, plus the team people...like 50 people every single time. And*  
33 *incredible healing to be able to say this and to have these people accept me and love me and*  
34 *care about me.”* This was a self-help group and was not led by a medical professional.  
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42 Participant E4.1 had severe congestive heart failure, untreated because of his Christian  
43 Science background. When he finally called a physician, who made a home visit, he said, *“I*  
44 *went from the darkest despair to bright hope. And that was because of him and what he said to*  
45 *me and how he said it and just the caringness of him.”* This physician, rather than being  
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51 judgmental about participant E4.1’s’s previous lack of care, accepted him as he was and gave  
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60 him hope..

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3 Participant E3.3 found another way to connect outside himself. He found healing in creating  
4 art. He said, "*When I'm either taking pictures with my camera, framing them, painting and*  
5 *sculpturing, that's my best. That's the best healer for me.*" This story illustrates that, although  
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10 there are common features, every healing journey is unique,.  
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#### 12 13 ACQUIRING RESOURCES AND SKILLS

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15 Making connections enabled participants to acquire and refine resources and skills that  
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17 were essential in their healing journey. People also brought their own personal strengths to the  
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19 journey.  
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24 A particularly important skill was *the ability to reframe* - that is to look at suffering  
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26 through a different lens. Participant E3.4, who was struggling with her history of sexual abuse  
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28 by family members, said of her therapist, "*I think I kept trying to convince him I was crazy. And*  
29  
30 *he kept saying, "No you're not crazy." He didn't pathologise, a lot of things he saw as a*  
31  
32 *reaction to some atrocious circumstances, rather than like the way you wouldn't necessarily say*  
33  
34 *a Vietnam Vet was crazy. You'd say they are responding like you'd expect to extraordinary*  
35  
36 *circumstances."* Participant E3.4 learned this skill from her therapist, and then was able to use  
37  
38 it herself. She said, "*And I think the meaning I was holding onto was ...not that this happened*  
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40 *because, but maybe a way to sort of put a positive spin on something that you can't ever imagine*  
41  
42 *to put a positive spin on would be for me to help other survivors and that would...I almost*  
43  
44 *started feeling stronger, like having this experience and survived it made me better than I would*  
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46 *have been otherwise"* She reframed the experience of abuse as something that made her stronger  
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48 rather than damaging her.  
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3 Participant P2.1, who had HIV infection said, *“I’m not the only one who have this*  
4 *problem. A lots, millions of people, you know. Little babies, little kids. They don’t have nothing*  
5 *to do with that. They have it, you know. I guess I have to live. And that was one of the things*  
6 *that used to keep me real stable.”* His ability to reframe his illness as something that could  
7  
8 happen to anyone made him able to realize that he was not to blame for his illness.  
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15 Another resource that people acquired or refined during their healing journey was **to**  
16 **choose to be positive** – that is to have some optimism about their situation. For some, being  
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18 positive was a trait they already had. For example, participant E1.1, who had diabetes, said,  
19  
20 *“Yes, you have to be positive. And like I said, it’s everything. I’m very positive. Honestly, I’m a*  
21 *very positive lady.* This was a personality trait, but still was a resource that helped her in her  
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23 healing journey.  
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30 Some people, however, learned to choose to be positive through their helping connections.  
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32 Participant P2.1 with his HIV infection was in despair and ready to die, but by connecting to his  
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34 sister he was able to change his attitude. After his sister visited him in the hospital and told him  
35  
36 she wanted him to be there for her wedding he said, *“I always not even thinking negative, You*  
37 *always gotta think positive. You always gotta think how beautiful life is.”* His sisters’ positive  
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39 attitude gave him hope and allowed him to learn to be positive.  
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45 A third essential resource that people acquired or refined was the ability **to take an**  
46 **appropriate amount of responsibility** for their healing journeys. They participated actively in  
47  
48 the process of healing. Once again, some participants already had developed this skill, and some  
49  
50 acquired or refined it from their helpers. Participant E4.3.2 , who was sexually abused as a child,  
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52 described the degree of participation required: *“You need a lot of energy and a lot of work...it*  
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3 *takes a lot of work. It doesn't just happen. It's not like a magic wand. "I'll go to the right*  
4 *doctor and boom."* He understood that he had to participate in his healing.  
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9 Participant J.3, who lost a child to SIDS, said, *"I have to contribute just as much as every*  
10 *therapist and then some, because I have to do it for myself. And if I'm not helping myself who*  
11 *the heck should? I'd better take care of myself and I've got to try and discern when something is*  
12 *necessary to be tended to or when something is not necessary to be tended to and know to*  
13 *differentiate the two."* Again, this participant illustrates taking appropriate responsibility for  
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healing.

Some people needed help in taking an appropriate amount of responsibility. For example,  
participant P2.3 was lost in the depths of substance abuse. She was taking so many pills that she  
went to sleep in the middle of a conversation in which she was asking for more pills from the  
psychiatrist at the methadone clinic. She describes what happened then: *"So, when I woke up...*  
*all the administrators from the program were in the office. And they said, "If you don't get help,*  
*we're kicking you off the clinic." So, they said, "You have a week." And they found me a place*  
*and I went through detox off the pills. And when I got off the pills, because I was so clouded*  
*up...when I got off the pills, it was like a rebirth. And I sort of had like a spiritual awakening*  
*and stuff came to me...and ever since then...I still struggled a little bit, but I started getting*  
*dedicated, I started making meetings."* The clinic administrators gave her a chance to accept  
responsibility rather than dismissing her from the clinic immediately.

#### EMERGENT CHARACTERISTICS

**Persistence** –People did not simply progress through this sequence and experience  
healing. The healing journey was a recursive, back and forth process. They found helpers,

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3 utilized the skills/resources that those helpers provided, found other helpers that provided more  
4 resources and utilized those skills and resources. As this process continued, people experienced  
5 a gradual amelioration of their suffering. Although many despaired at times, all demonstrated  
6 the quality of persistence – they refused to give up. Participant P2.3 said, *“And when I couldn’t  
7 see the light on the other side, I still struggled every day to live. I still struggled every day to live.”*

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16 As people struggled through their recursive healing journeys, several common  
17 characteristics began to emerge, which we document here with illustrative quotations:

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21 **Hope** – the expectation that there can be an end to present suffering. Participant E3.1,  
22 who suffered from Crohn’s disease, said *“I think gradually I realized that I was going to feel  
23 better. I did have days when I actually didn’t vomit, when I did feel better. And I think  
24 gradually I came to believe that maybe I could have a normal life again.”* Although slowly and  
25 fitfully, hope did emerge for this participant.

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33 **Self – Acceptance** – the ability to accept oneself as a valuable person . Participant P2.1  
34 said, *“I’m really proud of myself. I think that now I still want to live. I don’t want to die, and I  
35 really love myself a lot. I have a lot of comfort in myself.”* His self-acceptance emerged partly  
36 from his understanding that he was not to blame for his illness.

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43 **Desire to help others** – understanding that suffering gives the strength and experience to  
44 help others in similar situations. Participant P1.1 adopted a special needs child. She said, *“So, I  
45 think that’s what helped me plug along. I just don’t feel like... I always feel like I have to feel  
46 that I can do something for somebody else, not just always done for me. I didn’t want to feel just  
47 passive; I could be doing something for somebody else too.”*

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3           *Healing* – the re-establishment of a sense of integrity and wholeness. We found we could  
4 best understand healing as an emergent property of the complex healing journeys of individuals  
5 in the context of their lives. None of these people were cured of their illnesses, but all developed  
6 a sense of integrity and wholeness despite ongoing pain or other symptoms. To one degree or  
7 another they were all able to transcend their suffering and in some sense to flourish. Participant  
8 E3.1 expressed it this way:  
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17           *“I think the gradual realization through my stress class and everything was the*  
18 *acceptance of the fact that it wasn't going to go away. It did not go away, but it did not have to*  
19 *mean the end of my life in terms of never being able to do anything I enjoyed ever again, or*  
20 *being able to eat anything I enjoyed ever again.”* Her Crohn's disease was not cured, but she  
21 was no longer defined by her illness.  
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30           Participant P2.3 became a social worker. She said *“Yeah, and it's just like just*  
31 *connections, like the healing process is about like connecting to other people, like you're not by*  
32 *yourself in this world. ...So, it's like we're so attached; yet we're so disconnected. And I think*  
33 *that that's the mission is for connectedness, for wholeness.”* For her, healing and a sense of  
34 wholeness emerged from her connections with others.  
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### 43 Model

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46           From these themes we developed a **model**, illustrated in Figure 1. Moving clockwise  
47 from the upper left, the model shows that an initial physical/emotional wounding leads to  
48 suffering. The manifestation and degree to which the initial wound causes suffering is dependent  
49 on people's personal characteristics, relationships, and stage in the developmental life course.  
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3 People's healing journey is facilitated by persistence, and through developing a sense of  
4 safety and trust. This allows the person to make new connections to relationships with helping  
5 others and to acquire important resources, such as reframing, responsibility, and positivity.  
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10 Bridges develop between the various connections made, and resources that are acquired. Over  
11 time, these relationships and resources foster hope, self-acceptance and the desire to help others,  
12 leading, in fits and starts, to the emergence of a sense of wholeness and integrity that constitutes  
13 healing.  
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## 23 Discussion

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26 This study has demonstrated that the path to healing is not a simple, linear process, but  
27 rather, a complex journey that involves suffering, connecting with others, and acquiring needed  
28 resources. The journey requires persistence and the ability to find trustworthy relationships with  
29 others. As this recursive process continues, emergent personal properties of hope, self-  
30 acceptance, and helping others develop. Gradually a sense of integrity and wholeness develops  
31 despite continuing symptoms of the original insult or illness.  
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41 Our work adds a new perspective to the existing healing literature, most of which focuses  
42 on relationships between health care professionals and their patients. This is exemplified by  
43 Jackson in the nursing literature.<sup>10,28</sup> Egnew developed his definition of healing by analyzing  
44 interviews with physicians<sup>7</sup> and Hsu, et al developed their definition of healing in focus groups  
45 with physicians, nurses, clinical staff and patients.<sup>6</sup> Churchill, et al interviewed patients, but  
46 their focus was on qualities of physicians that patients felt contributed to their healing.<sup>14</sup> In  
47 contrast to much of this literature, our study focuses on how people experience the progression  
48 from illness and suffering to healing, something that has been reported in personal stories, but  
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3 has received little research attention. Relationships with health care professionals were a part of  
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5 that process but often not the most important part. This finding is in accord with sociological  
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7 studies, such as that the seminal work of Arthur Kleinman<sup>29</sup> who pointed out that all health care  
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9 takes place in a social context, involving three sectors: the popular sector that includes help from  
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11 family and friends, the folk sector, that includes accessing therapies not recognized by the  
12  
13 mainstream, and the professional sector. Our work emphasizes the complex and overlapping  
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15 interactions of these sectors in helping people along their healing journeys.  
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20 Recently, psychiatry has put emphasis on the need for recovery, even if the disease is not  
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22 cured, within their ‘recovery movement’<sup>30</sup> and one recent review suggested that the key  
23  
24 processes involved were connectedness, hope and optimism, identity, finding meaning, and  
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26 empowerment.<sup>31</sup> Again, this is in accord with our findings.  
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30 This study expands on the previous work of Scott et al,<sup>8</sup> which focused on the nature of  
31  
32 the healing relationship between physicians and their patients, but noted that other kinds of  
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34 relationships facilitated healing. The present study is unusual, as we have focused on the  
35  
36 experiences of ‘patients’ rather than professionals - a group of people on the slow journey from  
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38 illness and suffering to healing. Relationships with health care professionals were important, but  
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40 were only part of the process. Connections within and beyond the self, and relationships with  
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42 other people, animals or creativity, were similarly important.  
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47 Acquiring new resources and skills is something that is stressed by the recovery  
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49 movement, which tries to empower people to find the resources they need.<sup>30,31</sup> The narratives  
50  
51 that we analyzed suggest that in conventional, disease-orientated, primary and secondary care  
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53 settings, people had to find their own way towards both acquiring the necessary skills and  
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55 resources, and to making meaning of their problems. They had to accept responsibility for  
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3 themselves, reframe their experiences and choose positivity in order to make progress towards  
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5 healing.  
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9 Only when they had made some appropriate connections, acquired necessary skills, and  
10 persevered, could healing emerge, along with hope, self-acceptance and a desire to help others.  
11  
12 Even then, our informants often described continued suffering, but they were now able to  
13 function effectively: the key outcome of healing processes in the view of Cassel.<sup>2</sup> This concept  
14  
15 is also in accord with the Aristotelian ideas of flourishing and eudaimonia – the idea that we  
16  
17 should all live life to fulfill our capabilities (which vary according to constitution and illness), for  
18  
19 the sake of the whole community as well as ourselves.<sup>32</sup> Research on patients with chronic  
20  
21 illness has shown that this concept remains relevant to their ability to function well.<sup>33</sup>  
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29 There are limitations to our analysis. The patients in this study were purposefully chosen  
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31 by their physicians as likely to have experienced healing, and, as such, are likely to not be  
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33 representative of ill people in general – they were purposefully selected to have rich and deep  
34  
35 experience of the phenomena we were trying to elucidate. The resulting model, therefore, is  
36  
37 relevant to bringing hope to people who are suffering — hope that healing is possible. The  
38  
39 model also brings a sufficiently detailed description of the healing process that it may be useful  
40  
41 to individuals struggling to heal, or to people attempting to help them through the healing  
42  
43 journey. We do not presume, however, that healing always happens or is even always possible.  
44  
45 It is not our intention to contribute to a “cult of positivity”<sup>34</sup> to disparage those who have not  
46  
47 experienced a healing journey as we have described it. It is possible that the path to healing is  
48  
49 affected by sex, race, ethnicity, and a host of other factors that were not apparent in our small  
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51 sample. Thus, our findings cannot be used to generalize about the effects of demography, time,  
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53 place or culture. Although the interviews for this study were conducted ten years ago, it is  
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3 unlikely that the experience of illness, suffering and healing is any different today than it was  
4 then. Interview data have the inherent limitation of dealing with perceptions of respondents'  
5 experiences of events rather than observations of events themselves, but in this study the  
6 perceptions of respondents was exactly what we wanted to capture and individual interviews  
7 were a reasonable approach. Our analysis uses an interpretivist paradigm.<sup>35</sup> Researchers who  
8 adhere to other qualitative research paradigms, particularly the positivist paradigm may find fault  
9 with our analysis approach. Our interpretation of these data is inevitably influenced by our life  
10 experience. Others might view the data differently and come to different conclusions. The  
11 validity of our analysis, however, is enhanced by the training and experience of the analysis  
12 team, reflexivity (reflecting on our own experiences), and searching the data for disconfirming  
13 evidence after we identified themes.  
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30 The findings of our study, which describes the journey of healing may give hope to  
31 people suffering from illness and may suggest some strategies for them to use to begin their own  
32 healing journey. Programs designed to serve patients may use the findings to align their offerings  
33 and staff training with these stages of the healing journey. Health professionals should look at  
34 these findings not as minimizing their role in helping to facilitate healing, but rather putting that  
35 role in the larger context of their patients' healing journey. Every person in a healthcare setting  
36 from the physician to the janitor can help or hinder patients on their healing journey. Our  
37 findings also suggest that health professionals may want to help patients recruit other helpers,  
38 such as family members, co-workers or supervisors to facilitate their healing journeys.  
39 Understanding the pathways from wounding and suffering to the emergence of healing can  
40 inform and encourage individuals' healing journey, and may help others to be supportive of their  
41 fellow travelers in fostering healing.  
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4 www.icmje.org/coi\_disclosure.pdf and declare: all authors had financial support for meeting  
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7 previous three years; no other relationships or activities that could appear to have influenced the  
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23 for Integrative Health, Baltimore, Maryland.  
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28 **Data Sharing Statement:** The de-identified interview transcripts are available from the  
29 corresponding author upon request.  
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33 **Figure Legend:** Figure 1: Healing Journey Model  
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Scott, JG et al

Figure 1



Figure 1: Healing Journey Model

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**Domain 1: Research team and reflexivity****Personal Characteristics**

1. Interviewer/facilitator Which author/s conducted the interview?

The first author conducted all interviews, as stated on page 6

2. Credentials What were the researcher's credentials?

The interviewer is both a practicing physician and an academic with training and experience in qualitative research, as stated on page 7

3. Occupation What was their occupation at the time of the study?

Details of the research team and their occupations is given on page 7

4. Gender Was the researcher male or female?

The interviewer is male, and three of the four co-authors/data analysers are also male, as is apparent from the author list and notes of the analysis team recorded on page 7

5. Experience and training What experience or training did the researcher have?

The interviewer has some 10 years of qualitative research experience. All co-authors have some experience with qualitative research. Two have more than two decades of qualitative research experience, and three of them have previously published articles in peer-review journals based on their own qualitative research studies. See page 7

Relationship with participants

The interviewer had no relationship with the participants with the exception of five patients from his previous practice. See page 6

6. Relationship established Was a relationship established prior to study commencement?

There was no relationship established prior to study commencement other than telephone calls or emails to schedule the interviews. See page 6

7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research

The participants were given an outline of the nature of the research when asked to take part by their own physician, and were told that the interviewer was a physician and that the research was about healing. They then provided signed informed consent before the interview with the researcher took place – see pages 6 and 7

8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic

Participants were informed of the researcher's interest in healing and that the researcher was a physician. See page 6.

**Domain 2: study design**

## Theoretical framework

9. Methodological orientation and Theory What methodological orientation was stated to underpin the study?

e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis

As stated on page 8, the analysis was based on a modification of the grounded theory approach documented by Crabtree and Miller

Participant selection

10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball

As stated on page 6 the two-stage sampling strategy was based on a purposive approach designed to maximize the chance of finding the phenomenon under study.

11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email

Participants were first contacted by their physician who explained the purpose of the study (page 6). Then participants were contacted by the first author by telephone or email to schedule a time and place for the interview. See page 6.

12. Sample size How many participants were in the study?

Twenty three participants as stated on page 7

13. Non-participation How many people refused to participate or dropped out? Reasons?

**One physician did not select any of his patients. He initially agreed to do this but never provided any patients despite multiple contacts. There were no refusals among the participants that were contacted by their physicians. See page 6**

14. Setting of data collection

Where was the data collected? e.g. home, clinic, workplace

As stated on page 6, interviews were conducted at a place of choosing of the participant, and that was mostly in their own homes.

15. Presence of nonparticipants

Was anyone else present besides the participants and researchers?

There was no one present at the interviews other than the researcher and the participants. See page 6

16. Description of sample What are the important characteristics of the sample?

e.g. demographic data, date

The characteristics of the participants are documented on page 7

Data collection

17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?

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3 As stated on page 7, an interview guide was used **that was modified after iterative analysis of the**  
4 **first few interviews**

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6 18. Repeat interviews Were repeat interviews carried out? If yes, how many?

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8 There were no repeat interviews. See page 7

9  
10 19. Audio/visual recording Did the research use audio or visual recording to collect the data?

11  
12 As stated on page 7 the interviews were audio-recorded

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14 20. Field notes Were field notes made during and/or after the interview or focus group?

15  
16 Field notes were made after each interview. See page 7.

17  
18 21. Duration What was the duration of the interviews or focus group?

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20 As stated on page 6 interviews lasted between 1 and 3 hours.

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22 22. Data saturation Was data saturation discussed?

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24 The original analysis team analysed the interviews iteratively. When no new themes were emerging  
25 from the data, the team determined that data saturation was reached. See page 8.

26  
27 23. Transcripts returned Were transcripts returned to participants for comment and/or correction?

28  
29 Transcripts were not returned to the participants. See page 7

### 30 **Domain 3: analysis and findings**

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32 Data analysis

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34 24. Number of data coders How many data coders coded the data?

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36 As stated on page 8, all interviews were initially coded by the lead author. In addition, pairs of co-  
37 authors coded most of the interviews separately and discussed their coding during the conference  
38 calls

39  
40 25. Description of the coding tree Did authors provide a description of the coding tree?

41  
42 Our immersion crystallization method does not use a formal coding tree. See page 8

43  
44 26. Derivation of themes Were themes identified in advance or derived from the data?

45  
46 Themes were derived from the data. See page 8-9.

47  
48 27. Software What software, if applicable, was used to manage the data?

49  
50 Altas-ti, qualitative software was used. See page 7

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52 28. Participant checking Did participants provide feedback on the findings?

53  
54 Participants were unable to provide feedback on the findings because the data were de-identified.  
55 See page 9

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57 Reporting

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59 29. Quotations presented Were participant quotations presented to illustrate the themes / findings?  
60 Was each quotation identified? e.g. participant number

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Quotations were used extensively and were identified by participant number. See pages 9-16

30. Data and findings consistent

Was there consistency between the data presented and the findings?

The themes were derived directly from the text of the interviews consistent with the principals of grounded theory. See page 8

31. Clarity of major themes Were major themes clearly presented in the findings?

Major themes are clearly identified by section (pages 9-16) as well as graphically represented in a model. See Figure 1.

32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?

One minor theme is discussed. See page 12