

Fig 1. *Survey participation*

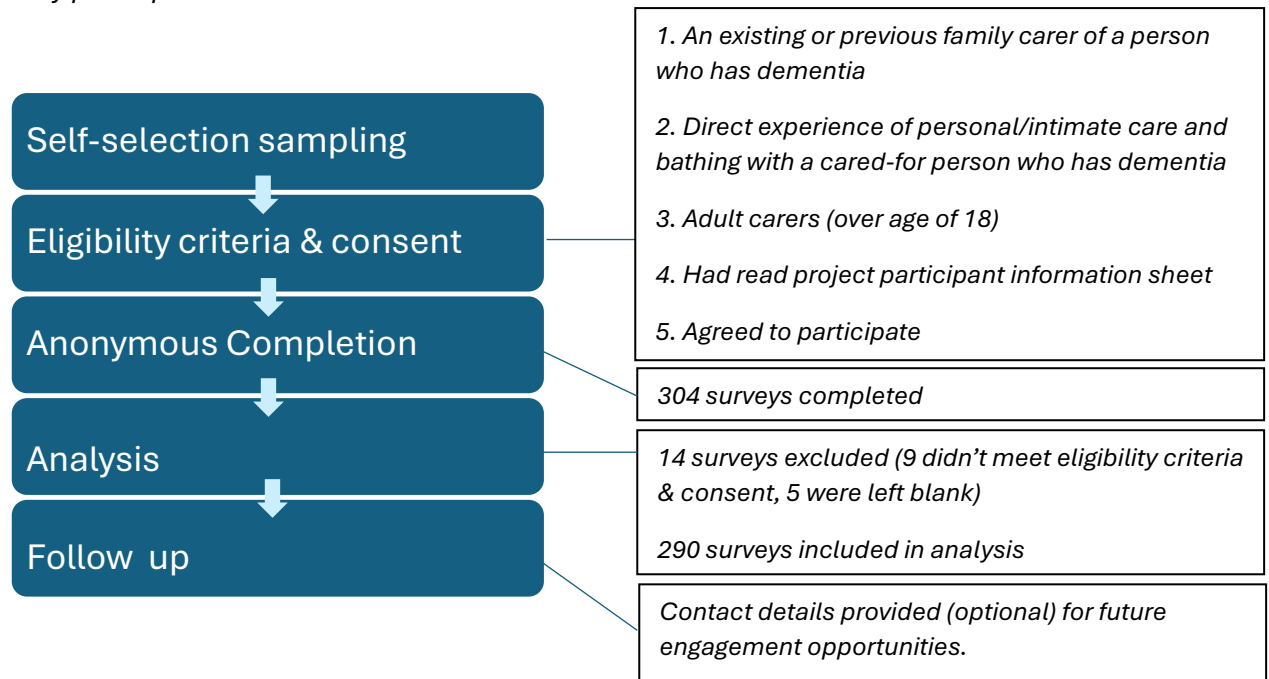


Fig 2. *Interview*

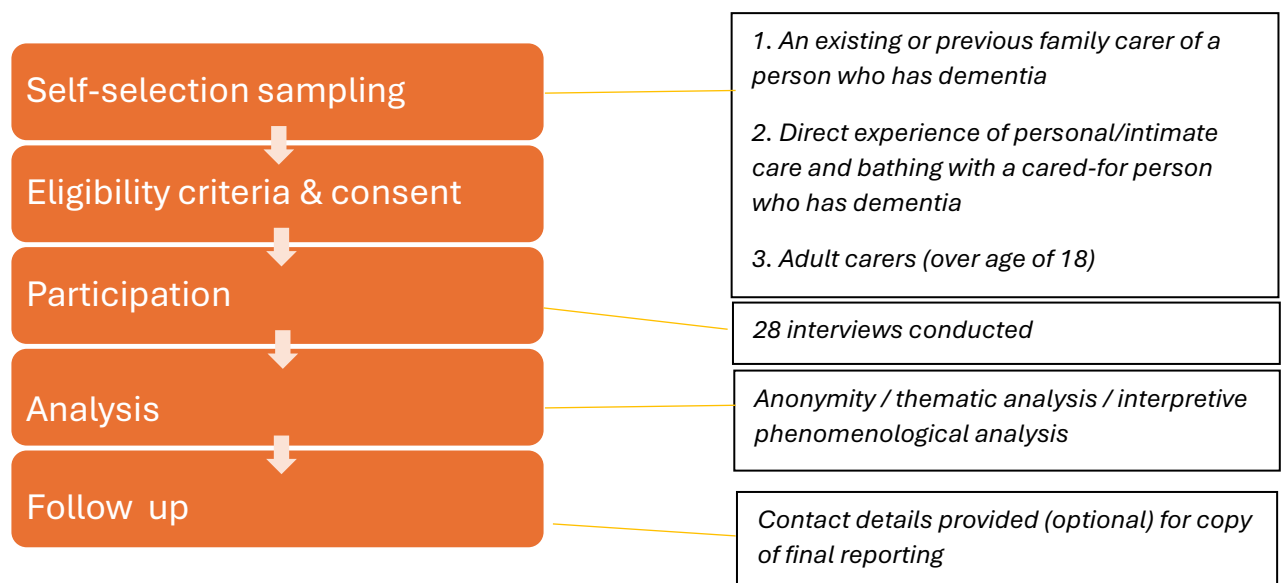


Table 1. *Survey demographics*

Characteristic	Topic/Category	Frequency (%)
Age when first providing personal care	Under 35	16 (5.5%)
	35 to 44	22 (7.6%)
	45 to 54	58 (20.0%)
	55 to 64	91 (31.4%)
	65 to 74	64 (22.1%)
	75 and older	31 (10.7%)
	Prefer not to say	8 (2.8%)
Gender	Male	57 (19.7%)
	Female	229 (79.0%)
	Other/Prefer not to say	4 (1.4%)
Ethnicity	White British	267 (92.1%)
	White Irish/Other White	8 (2.8%)
	Non-White or Other	8 (2.8%)
	Prefer not to say	7 (2.4%)
Religion or belief system	No religion	98 (33.8%)
	Christian	179 (61.7%)
	Other religion	7 (2.4%)
	Prefer not to say	6 (2.1%)
Relationship to care recipient	Spouse/Partner	144 (39.3%)
	Child	146 (50.3%)
	Grandchild	7 (2.4%)
	Other family member	12 (4.1%)
	Friend	3 (1.0%)
	Other	8 (2.8%)
Living status with care recipient	Live together	160 (55.2%)
	Live separately	127 (43.8%)
	Prefer not to say	3 (1.0%)
Frequency of providing personal care	Daily	198 (68.3%)
	More than once per week	54 (18.6%)
	Once a week	6 (2.1%)
	Other	28 (9.7%)
	Prefer not to say	4 (1.4%)
Length of time providing personal care	Less than 1 year	24 (8.3%)
	1 to 2 years	67 (23.1%)
	3 to 5 years	103 (35.5%)
	More than 5 years	96 (33.1%)

Table 2. *Survey findings: experiences of providing personal care*

	Topic/Category	Frequency (%)	
Impact of providing personal care	Presence of negative effects	Yes	252 (86.9%)
		No	35 (12.1%)
		Prefer not to say	3 (1.0%)
	Presence of positive effects	Yes	175 (60.3%)
		No	108 (37.2%)
		Prefer not to say	7 (2.4%)
	Affected relationship with person with dementia	Yes	172 (59.3%)
		No	114 (39.3%)
		Prefer not to say	4 (1.4%)
Issues and challenges of providing personal care	Face challenges providing personal care	Yes	238 (82.1%)
		No	47 (16.2%)
		Prefer not to say	5 (1.7%)
Help and assistance in providing personal care	Ability to access help and assistance	Yes	186 (64.1%)
		No	95 (32.8%)
		Prefer not to say	9 (3.1%)
	Receiving help from others	Yes	169 (58.3%)
		No	116 (39.3%)
		Prefer not to say	7 (2.4%)
	Evaluation of help from others (usefulness)	Yes	171 (59.0%)
		No	7 (2.4%)
		Prefer not to say	112 (38.6%)
	Awareness of aids and adaptations	Yes	254 (87.6%)
		No	28 (9.7%)
		Prefer not to say	8 (2.8%)
	Use of aids and adaptations	Yes	196 (67.6%)
		No	84 (29.0%)
		Prefer not to say	10 (3.4%)

Table 3. *Interview demographics*

Characteristic	Topic/category	Number of participants
Age range	Under 35	2
	35 to 44	4
	45 to 54	4
	55 to 64	7
	65 to 74	7
	75 and older	4
Gender	Female	18
	Male	10
Ethnicity	White British	22
	White	1
	Chinese	1
	African	1
	Mauritian Asian (Indian heritage)	1
	Asian	1
	British, Pakastani	1
Sexual orientation	Heterosexual	22
	Homosexual	1
	Not stated	5
Faith or belief system	Christian denomination	12
	Muslim	2
	N/A	11
	Atheist	1
	Hindu	1
	Jewish	1
Registered as disabled	N/A	5
	Yes	1
	No	22
Long term health conditions	Yes	16
	No	10
	N/A	2
Relationship to person living with dementia	Daughter	11
	Husband	6
	Wife	2
	Granddaughter	2
	Grandson	1
	Partner	2
	Civil partner	1
	Spouse	1
	Son	1
Living situation	Separately	15
	Together	13

Table 4. *Combined survey and interview concepts and themes*

Concept	Themes
General observations about being a carer and assisting with personal care	<p>Personal care is a term for a range of overlapping activities, some of which individual carers are more comfortable assisting with than others.</p> <p>Personal care can be demanding, in different ways: on the time, finances, emotions, responsibilities and daily lives of carers, whether living separately or together, or accompanying someone to go out.</p> <p>Preparedness (including prior knowledge and experience of dementias and/or personal care) makes a big difference - but there is a gap between having knowledge and the reality of caring for someone.</p> <p>The previous quality and nature of the relationship with someone before their dementia makes a big difference (positive and negative).</p> <p>People living with dementia can be reluctant to accept help or care, which could be to do with their understanding, physical comfort, or desire for independence and dignity.</p>
Getting help from health and social care services	<p>The onus is on carers to seek out and engage with information and support but doing so is emotionally and physically demanding.</p> <p>Support from care professionals needs to be more consistent, reliable, person-centred and collaborative with families to avoid tensions and problems.</p> <p>Health and social care providers and services in the dementia care pathway need to be better integrated, with better and more timely communication between them and with families.</p> <p>The benefits of support services that are on offer in the community need to be clearly explained, person appropriate and accessible.</p> <p>Aids, adaptations and gadgets need to be tailored to people's personal preferences, circumstances and environment in order to be useful.</p>
Strategies that carers might use in assisting with personal care	<p>Approaching personal care with the aim to make it a better experience can be very effective to put people at their ease and carry out tasks (e.g. use of humour, playing music or singing together, as appropriate to the person).</p> <p>Supporting people to continue practicing their lifelong routines, personal preferences and beliefs is both helpful and respectful.</p> <p>Time needs to be taken to work with the person being cared for to plan doing personal care with clear communication throughout.</p>
Issues for carers in looking after their emotional and physical health and wellbeing	<p>Carers can experience multifaceted, ongoing and overwhelming feelings of guilt and negativity around their caring role.</p> <p>Carers can experience pride and satisfaction in being able to support and provide personal care.</p>

	<p>Carers can experience feelings of stigma and shame around providing personal care, and may not know how to talk about it or with whom.</p> <p>A united and supportive (chosen) family unit working together creates a more positive experience for all.</p> <p>Carers need breaks and personally effective strategies to look after their own mental and physical health (formal and informal).</p>
--	--

Table 5. *Interpretative phenomenological analysis (IPA) group experiential themes*

1	United or alone: the role of friends and family
2	"She's here, she's safe": respect, dignity and person-centred care
3	"I love her but...": the pull of conflicting emotions
4	Trapped and abandoned: overwhelming feelings of responsibility
5	Adjusting to change: navigating the unknown
6	Plans and preparation: a systematic approach
7	Access to support: an endless struggle
8	"It's difficult and they don't care": broken relations with professionals
9	Who am I?: reconciling the past and the present

Adverse events

There were no adverse events associated with this trial.